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Putting Acute Care on the Health Care Agenda

A Study of Discharged Hospital Patients into the Community

Submitted in partial fulfillment
of the degree of Masters of Philosophy

The Open University

April 1990

Olga Bright

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Abstract

This research examines acute patients discharged from hospital to the community. The work is based on interviews with forty-five economically active and retired patients discharged from the Milton Keynes District General Hospital. The research shows that the needs of acute care patients are similar to, and often greater than those of the 'priority groups', the elderly, the disabled and the handicapped. In the light of present trends towards early discharge, the research directs attention to the conceptual and the practical problems of current community care policy. The thesis examines the relationship between the hospital, the community health professionals and the family. It shows that there is not only a move away from institutional care but also a move away from professional care to lay care. Current health policies have an implicit expectation that patients should become knowledgeable 'consumers' of health care. The study uses the concept of the convalescent career to explore the transition from the hospital to the community, and recommends a broader interpretation for the provision and distribution of health and social services in the community.

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Chapter 1

Changing Philosophy and Policy for Acute Care

Acute care in the community has become an issue as a result of current health and social service policy. This chapter explores the policies, the data and the theoretical issues which pertain to acute care in the community. An analysis of the respective government reports indicates conflicting objectives, assumptions and funding recommendations. The consultative document *Priorities for Health and Social Services* [DHSS, 1976a] was the key driving force behind current trends for reducing hospital length of stay, increasing hospital throughput and placing acute convalescent patients into the community earlier. Nevertheless, the Community Care policy, [DHSS 1959, 1971, 1975, 1981.] is directed towards the care of the priority groups, discharged from long stay institutions. The historical development of the Community Care policy, with its exclusive focus on specific 'priority groups', is in sharp contrast with the recommendations of the Resource Allocation Working Party [RAWP] [DHSS, 1976c] a contemporaneous government report. The philosophical and practical emphasis in the Community Care policy is a greater reliance on the individual, whereas the

RAWP report recognises the structural forces which influence patterns of ill health. The implications of the government documents raise theoretical and practical issues, about the shifting responsibility for health between the state, the individual and the community, as well as a changing perception of the causes and cures of disease. Ill health has been related to structural factors, environmental factors and individual factors. This shifting of perception is articulated and reflected in changing government health and social service policy.

National data is presented on hospital and community expenditure, levels of health and social service provision, length of stay, hospital throughput, and the distribution of morbidity and mortality . Comparing the national data with regional and Milton Keynes district data, provides a comparative understanding and demonstrates the problem of acute care in the community health care policy. The data suggests that the reduction in costs per inpatient, combined with increased hospital throughput, raises potential problems for acute convalescent patients in the community.

The philosophical problems, statistical data and the theoretical issues point to the need for research into acute convalescent care in the community. This research follows the career of 45 patients discharged from Milton Keynes District

Hospital ,an NHS hospital, in England. It is the study of the needs and the caregiving for patients discharged from medical and surgical wards to the community. Specifically the research is concerned with the needs of acute convalescent patients and the informal and formal after care they receive. It compares acute convalescent patients across as well as within particular population groups, between the economically active and the retired, and between men and women. It seeks to explore the differences and similarities of acute convalescent patient's needs vis a vis the 'priority' groups. The research considers the relationship between patient needs and the nature , type and timing of the after care, which patients receive from lay and professional sources.

I. Philosophy

The issue of acute care patients in the community is a problem which originates with the development of contemporaneous government publications; the development of the Community Care Policy [DHSS, 1971; DHSS, 1981a, 1981b], Priorities for Health and Social Services [DHSS, 1976a] and the RAWP report [DHSS, August,1976] The problem of acute care in the community is rooted in the different philosophic orientations of these respective policies. This chapter presents an

analysis of the implicit philosophical assumptions and contradictory objectives of the community care policy and the implications it has for acute care patients. Specifically, this analysis demonstrates the contrasting assumptions about the responsibility for illness of these respective policy documents and the problem of inequalities in health and the nature of illness as well as the limited scope of the community care policy.

Tracing the historical context of these policies, within the history of the NHS, indicates a shifting of responsibility between the state and the individual. The original conception of the NHS was based on the premise that everyone had the right to health care. It was founded on the assumption that health care should be provided on the basis of need regardless of income and that a high quality service could be provided free on the point of delivery. This policy implicitly recognised that health and ill health is a product of structural forces as much as individual actions. The current policies reflect a changing philosophy of health care. It increases the responsibility of the individual, as a result of increasing government financial pressures.

The history of the community care movement reflects a shift from a focus of the provision of health care through the centralisation of resources in hospitals and similar

institutions to the community. This was evident in the publication of the Mental Health Act [DHSS, 1959] and the growing concern over the elderly confined to institutional care. A growing disillusionment with institutional and professional care led to government reports recommending care in the community. In 1971 , a White Paper entitled Better Services for the Mentally Handicapped [DHSS,1971] led the way to a twenty year shift from a hospital based service to a community based one. In the following years, Better Services for the Mentally Ill [DHSS,1975] and Growing Older [DHSS, 1981b] were published recommending community as opposed to institutional care for the mentally ill and the elderly. These reports were based on an emotional appeal against the conditions of large institutional care in favour of the prospect of warm caring ties in the community. Thus early on in the history of community care, the elderly, the mentally ill and later the disabled became groups for particular concern. In the 1960's and 1970's with the publication of such influential books as Asylums [Goffman,E.,1961] and Medical Nemesis [Illich,I.,1976] public opinion was shaped away from institutional care and professional autonomy. It was within this context of changing public and political opinion that a "dialectic of anti-institutional and pro-community ethos developed." [Henwood,M., 1986, p.147.] Nevertheless, the Community Care policy only gradually came to be implemented as it came to be perceived as a method of reducing NHS capital

expenditure. Thus while the original conception of the community care policy was one of caring and concern for the treatment of, and conditions of people placed in long term institutional care, it actually became implemented in a political climate which emphasised the need to cut public expenditure and to 'roll back the state'. It reflected a shift in a "changing balance between public and private responsibility in personal care" [Henwood,M., 1986 p.161]. Indeed, Margaret Thatcher's speech [Feb. 19, 1981] to the Women's Volunteer Service National Conference, ' Facing the Challenge ', encapsulates and directs current government thinking on health and social service policy , when she said " I think that the statutory services can only play their part successfully if we don't expect them to do things that we can do for ourselves."

A clear formulation of the Community Care Policy [CCP] came with the White Paper Care in the Community [DHSS, 1981a]. This formalised the objectives of the community care policy. It states that the Care in the Community initiative is aimed at helping long stay hospital patients unnecessarily kept in hospital to return to the community. It was primarily referring to the discharge of the 'priority groups', the mentally handicapped, the disabled and the elderly from long stay institutions. The community was conceived of as a resource composed of friends, relatives, statutory services

and volunteers living within close proximity, who were both available and willing to help. The broad ideological appeal, among political parties of all persuasions for the Community Care policy was based on people's "associations of locality, friendship,, close knit social networks, mutually supportive activity and a pattern of relationships which is warm, reciprocal and self sustaining" [Boswell,D. 1985].

In 1976 the consultative document Priorities for Health and Social Services [DHSS, 1976a] was published. This report reflects the challenging economic problems facing the NHS in the late 1970's and 1980's. Its' importance for acute care patients is a result of its budgeting recommendations . Priorities for Health and Social Services is essentially a financial report which seeks to allocate resources between different NHS client groups, within the context of a shrinking budget. The report recommended that priority should be given to provision for the care of the mentally handicapped, the mentally ill and the elderly and that "there must be a deliberate decision to give them priority over the development of the general and acute hospital services" [DHSS, 1976a, Introduction p.2] It suggested that a primary means of funding the 'growth money' for the priority groups would be acheived by reducing the average length of stay of acute patients. "If the average length of stay could be reduced ... there would be a potential annual saving of the order of £ 26m

in "hotel" costs." [DHSS, 1976a ,Section IV, 4.22] The PHSS states " there is a need to use low cost solutions for the ever increasing demand for health care." [DHSS, 1976a, Section 19, p. 819] The transfer of care from high technology , capital intensive professional care to the community composed of friends, relatives and volunteers was recommended as the way forward.

The PHSS document envisaged that the District General Hospitals would offer a full range of specialised treatment, including a psychiatric unit, geriatric unit and maternity units. The expansion in demand by the growing number of elderly people would be reflected in geriatric and orthopedic provision, thus reducing the relative importance of other patients in the acute hospital sector, particularly those in medical and surgical wards. The PHSS report, also recommended that particular attention should be paid to the rapid development of health and social service support, notably home nursing [and health visiting], meals on wheels and home help services for the care of the priority groups in the community. Thus both within the hospital and within the community the policy directive is to redirect expenditure and manpower for particular sections of the hospital community. At the same time it recommended increasing the hospital throughput of the acute section of the hospital by reducing lengths of stay and discharging patients earlier into the community.

The economic rationale behind the early discharge schemes is based on the fact that the first three days in hospital are the most expensive due to the costs of diagnostic facilities, medical and nursing care and prescriptions. It is argued that as the length of stay increases, the patient convalesces, increasing proportions of the costs are fixed, such as , heating, lighting, and general nursing services .Increasing hospital throughput with an early discharge policy will effectively mean that those patients undergoing such treatment will receive only the most expensive part of hospital care. However, it may be that the net effect for hospital expenditure will rise as it treats more patients, even as the cost per case may fall. Thus NHS hospital expenditures may continue to consume the lions share of NHS monies, in absolute and relative terms to general practitioner and community expenditure.

In the light of the governments belief that NHS resources needed to be managed efficiently the NHS Management Inquiry Team [DHSS, Oct., 1983] recommended a new model of NHS management. It recommended that members of the medical profession must be ready to seek more economical methods of providing services. Hospital consultants and doctors were in effect being asked to organise their modes of treatment in the light of demands for greater efficiency. It therefore placed

consultants and general practitioners at the cutting edge of professional expertise and discretionary management. One effect of this has been gaining the co-operation of the hospital doctors to reduce the length of hospital stay and to discharge patients to the community earlier.

In summary , the analysis of the Community Care Policy, Personal Health and Social Services and related reports indicates that within the triangle of responsibility for health care; consisting of the hospital, the community professional services and the individual, there are shifting boundaries in the responsibility for health care. This has three implications; one, increased emphasis on the role of the individual and a de-emphasises the structural factors associated with ill health, secondly, there is a shift in the balance of professional care and lay care and, thirdly, the social and economic costs of health care are increasingly placed on the individual as opposed to the institution, or more specifically, the state.

In juxtaposition to the individualistic orientation of the CCP and the PHSS, a contemporaneous government report, the RAWP [DHSS, 1976] report, recognised the centrality of structural factors as determinants of health, morbidity and mortality. It explicitly argued that social and demographic factors were major influences on inequality of health. It recognised not

only the inequalities in the existing allocation of funding arrangements for different regions, but also that different regions had different levels of need. RAWP saw as its' underlying objective to achieve equal opportunity of access to health care for all people at equal risk. Therefore the RAWP report explicitly recognised two aspects which the consultative document Priorities for Health and Social Services and the Community Care policy obscure; that ill health is a wider problem than that of specific client groups and secondly, that the cause of ill health may lie outside individual actions and be related to broader, social structural factors.

The Black Report [Townsend,P. and Davidson,N., 1982] consolidated the evidence of continuing inequality in health, in Britain. It presented data which demonstrates that ill health increases with declining social class. Furthermore the distribution of ill health is not confined to the elderly but doubles in the 45-64 year old age group. It points to the fact that morbidity and hospitalisation are a part of all stages of the life cycle. The Black Report and more recently The Health Divide: Inequalities in Health in the 1980's [Whitehead,M. Health Education Council, 1987] supplies additional data to support the argument that ill health is associated with structural factors outside the control of the individual. In the light of the policy of discharging

patients into the community earlier, placing an increasing responsibility on lay, rather than professional care, the data on the structural factors associated with ill health presents disturbing evidence of potential problems of acute convalescent care in the community.

Comparing the philosophical and practical implications of these reports, it is apparent that there is a common theme of reducing NHS expenditure and an emphasis on the provision of care on a geographical basis. The important differences between the Community Care policy, the report Priorities for Health and Social Services and the RAWP report revolve around the objectives, assumptions, and the concept of 'need'. Central conflicts emerge over financial versus humanitarian objectives in health care policy. In other words, can health care be provided 'by the community', at the same time as there are regional disparities in need and funding allocation. The emphasis of the CCP is on the 'warm and caring networks of families and friends', but in practice it is a policy which 'rolls back the state', in spite of individual and regional disparities in need. In contrast, the PHSS paper recommended providing finance for specific client groups; the elderly, the disabled and the physically and mentally handicapped, in the community, at the 'expense' of acute care in-patients [as distinguished from geriatric wards]. The objective of the RAWP report was to provide NHS financing on the basis of need,

leaving social service funding largely determined by the numbers of the elderly. In allocating resources on the basis of need the RAWP report recognized 'need' as a broader concept than specific client groups. The implicit assumptions of these reports suggest that a central difference between individual versus structural factors of ill health. A central tension exists, therefore, between these reports on the role and provision of statutory care, funding priorities and the responsibility for health care. The implications of these reports, for acute convalescent care in the community, is a result of the lack of government initiatives or recommendations for their after care. This makes it necessary to evaluate the continuity of their care in the community.

In the light of these policies and government documents it is necessary to examine NHS expenditure patterns, National and District patterns of average length of stay , numbers of in-patients and national morbidity and mortality data in order to demonstrate the magnitude of the problem of acute convalescent care in the community.

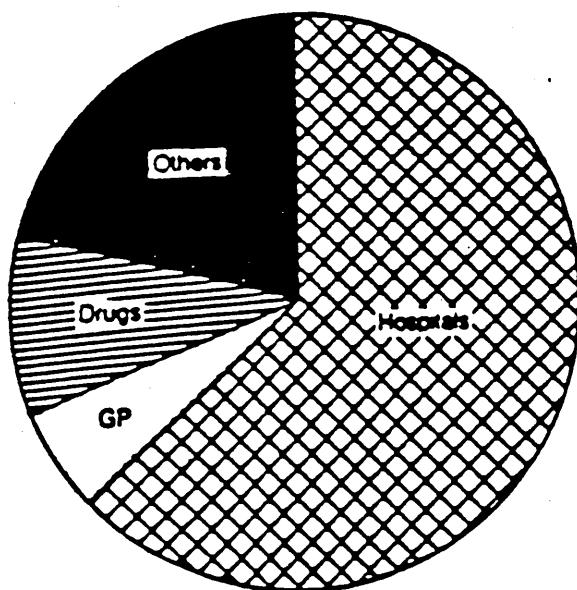
II. Policy Implementation, NHS Hospital and Community Expenditure

Net spending on the NHS in 1980/81 accounts for 11% of all public expenditure. Nevertheless the demand for services, the increasing cost of services and capital equipment have forced successive governments to reduce real expenditure. The debate on NHS funding centers on a tension between hospital, community and general practitioner expenditure as well as a tension between competing RHA's for funds.

Over two-thirds of NHS funds go on current expenditure for the hospital and community health services, and most of the remainder on the family practitioner services [DHSS, 1981a]. In terms of the hospital versus community expenditure, hospital expenditure comprises approximately 61% of total expenditure with community expenditure comprising only 6% [OHE Compendium, 1980, Table 1.3]. Figure 1 shows the breakdown of gross NHS expenditure, with the hospital sector receiving the largest share. The hospital services have always been the most expensive part of the NHS and their share of total costs has increased, while the share of general medical services has declined [Fry, J., 1985]. Despite the large number of policy documents [DHSS, 1959; DHSS, 1971; and DHSS, 1976a; DHSS, 1981] which have recommended the implementation of

community care there has only been a limited shift of resources away from the hospital to the community. Between the years 1976/77 and 1981/82 expenditure on the community health services overall rose from 584 million pounds in 1976/77 to 665 million pounds in 1981/82, an average yearly increase of just 2.6% [Fry,J, 1985].

Figure 1. NHS Gross Expenditure-Hospitals, General Practice and Drugs [1980]



[Source: OHE Compendium, 1980, Table 1.3]

Regional differences in health and social service expenditure were found to be extensive by the Resource Allocation Working Party [DHSS, 1976c]. More recently, the Audit Commission's [Audit Commission, 1986] report on community care found that social service expenditure, and implementation of the 'care in the community' initiative varied both within and between

regions. The levels of social service expenditure, level and types of social service provision vary across and within departments. Therefore the overall figures of expenditure give only a broad indication about the chances of receiving a particular service in a particular place [Audit Commission , 1986]. Indeed, the evidence suggests that the care the priority groups receive is dependent more on where they live than on 'need'. Variations in Local Authority expenditure on services does not reflect local demand, as disparities exist both between and within regions. The Audit Commission concluded that "community care is far from being a reality in many places" [Audit Commission, 1986 p.2]. Only in some areas, such as in Kent, Devonshire and Oxfordshire has there been a thrust of care in the community initiatives and that these initiatives are primarily orientated towards the elderly and to a lesser extent to the mentally ill and disabled .

Joint planning arrangements were developed in 1974 in order to promote a coordination in the provision of community care and to provide a bridge between health and social services. In the Circular of 1976 [DHSS, 1976b] the government proposed joint financing projects with the local authorities. The aim was to provide joint funding and planning for mentally handicapped, mentally ill, elderly and the disabled. Initially, a modest 8 million pounds was spent on joint funding projects, which rose to 85 million in 1982/3. However,

the Audit Commission points to the fact that "progress with the build-up of community based services has generally been slow, and in some places is not keeping pace with the run-down of long stay institutions" [Audit Commission, 1986, p.2]. Furthermore, Tyne [Tyne,A.,1982] argues that little information is available on what joint funding has been used for and that so far it has been difficult to gauge the effect of joint funding. Tyne argues that it is " a marginal resource designed to effect minor redistributions within the Better Services pattern, of two distinct services." [Tyne,A. 1982, p.148] There is concern that joint funding is being used to provide additional funds for existing projects without creating new schemes.

Summarizing extensive research Walker [Walker,A., 1982] concluded that there has been a shortage of resources, poor conceptualisation of statutory care and a lack of coordination between social services in the implementation of community care. Thus, in practice the CCP is about a changing balance of services, with the family playing the major role. Walker's conclusions raise important questions for the study of acute care in the community. One, is a result of the fact that the evaluations of community care have concentrated on the implementation of community care for the priority groups discharged from long stay institutions. Research has therefore focused on the needs of long term care groups and this has led

to an examination of client needs in relation to social service support and less attention is directed to medical community services. Secondly, the shortfall of provision for the 'priority groups' suggests that patients discharged from short stay acute wards will have even less opportunity of receiving services, regardless of need.

Table 1 shows expenditure per head of population [reworked from Social Trends 1985]. The table demonstrates considerable regional variation in health care expenditure. Oxford RHA, which has Milton Keynes within it's authority, has the lowest per capita expenditure.

Table 1. Regional Health Authority Expenditure per Head of Population 1984

Region RHA	Expenditure [millions]	Population	Expenditure per capita
Oxford	489.9	2,375.8	206.2
Trent	999.7	4,602.6	217.2
Wessex	614.7	2,802.0	219.3
W. Midlands	1,146.5	5,176.5	221.5
E. Anglia	427.7	1,925.2	222.1
Yorkshire	836.0	3,598.0	232.3
S. Western	740.1	3,101.3	238.6
Northern	743.5	3,100.1	239.8
S.W. Thames	728.2	2,948.2	247.0
Mersey	607.4	2,434.0	249.5
N.W. Thames	881.1	3,455.9	255.0
N. Western	1,040.8	4,005.3	259.8
S.E. Thames	948.6	3,585.6	264.5
N.E. Thames	1,059.8	3,735.6	283.5

[Source: reworked from Regional Trends 20, 1985 edition, Tables 4.1 and 4.3]

In the wake of the community care policy, a growth of interest in community based services has developed. This is reflected in the growing numbers of health centers, based on particular localities and the growing movement of the 'Patch' system for social workers [Bayley,M.J., 1982; Baldock,J., 1986]. In general practice there has been a trend to larger partnership groups, with a centralisation of community services . In fact, the number of general practice units has declined nationally by 24% between 1952 and 1980 [Fry,J., 1985], with the growth of health center practices. Table 2 indicates that numbers of hospital based doctors between the years 1949 and 1980 has far exceeded the numbers working in general practice. Despite the fact that hospitals have had a 10% increase in throughput in recent years, and the practice of earlier discharge the numbers of primary health care doctors have not reflected a commensurate increase in the numbers of patients discharged. [Figure 2]. Table 2 compares the number of hospital versus community doctors and nurses. It demonstrates the large growth in hospital based physicians, and brings into question the implementation of the growth of primary health care services, in view of the 'double numbers ' being discharged into the community. Table 2, also shows the overall increase in the numbers of nurses. However, as Care in Action reported that "the overall rise in the number of nurses masks considerable geographical variation and there is still concern about the availability of appropriately qualified nurses"

[DHSS,1981,p.25].

Table 2 Medical and Nursing Staff in Hospital and General Practice, 1949 - 1980.

Health Service Personnel Change	1949	1980	%
Doctors: Hospital	11,735	31,421	168
General practice	18,000	22,674	26
Nurses: Hospital	137,636	297,684	116
Community	9,529	32,162	238

[Source: Fry,J., NHS Data Book, 1985]

Table 3 gives an analysis of the regional variations of community nurses. It compares community nursing staff in a few RHA's [reworked from tables in Social Trends 1985]. Again, Oxford RHA, has one of the lowest growths between the years 1978 and 1983, despite the rapidly growing new city within its region, the opening of the new Milton Keynes District Hospital and that it has one of the shortest lengths of stay [Table 4].

Table 3. Changes in the Number of Primary Health Care Nursing Services ,for Selected RHA's, 1978 - 1983.

	Midwives	Health Visitors	District Nurses
Oxford RHA	+68	-4	+34
Yorkshire RHA	+79	+91	+171
Trent RHA	+135	+141	+205
Northeast Thames RHA	+70	+74	+133
Southeast Thames RHA	+43	+67	+188
West Midlands	-26	+109	+204

[Source: reworked from Social Trends , 1985]

Table 4. Average Length of Stay for Medical and Surgical Patients, 1971 to 1983, England and Milton Keynes.

England

Average Length of Stay (days)

	1971	1976	1979	1980	1983	1988
Medical Patients	14.7	12.1	11.0	10.6	10.3	9.7
Surgical Patients	9.1	8.6	8.1	7.8	7.3	6.7

[Source: Social Trends 1984 - 1985 , Table 7.20 National Health Services Summary: all specialties]

Milton Keynes

	1986	1988
Medical Patients	8.2	8.8
Surgical Patients	5.3	5.7

[Source: Milton Keynes Health Authority, Dept. of Community Medicine, District Information Unit, Quarterly Information, Oct.-Dec. 1986 and 1988]

These tables confirm that there is considerable regional variation. Oxford RHA, in particular conforms most closely to the government recommendations, with the lowest expenditure per capita and the shortest length of stay. Interpretation of these figures must also be understood in relation to hospital throughput. Table 5 indicates that hospital throughput increased by 10% between 1971 and 1983. This has been achieved by a reduction in the average length of stay, [Table 4]. Both the earlier discharge of patients and the increased throughput places additional burdens on limited community medical and social services.

The national lengths of stay can be roughly compared to the lengths of stay in the District General Hospital of Milton Keynes. It can be seen, allowing for a further national reduction in the average lengths of stay, since 1983, that the Milton Keynes lengths of stay are competitive if not significantly shorter.

The PHSS White Paper recommended both shorter lengths of stay and higher throughput for hospital patients. Table 4 and Table 5 indicate that this has occurred. Table 5 demonstrates the age and sex distribution of ill health and a higher throughput, based on reworked GHS data.

Table 5. Hospital Inpatients, Retired and Economically Active Age Groups

1973			
Age	Males	Females	Total
45 - 64	429,040	455,840	884,880
65 +	311,460	378,480	689,940
Total	740,500	834,320	1,574,820

1982			
Age	Males	Females	Total
45 - 64	408,080	423,840	831,920
65 +	354,320	420,840	775,160
Total	762,400	844,680	1,607,080

1983			
Age	Males	Females	Total
45 - 64	359,730	425,840	785,570
65 +	352,540	444,060	796,600
Total	712,270	869,900	1,582,170

1984			
Age	Males	Females	Total
45- 64	413,520	427,520	841,040
65 +	317,400	526,700	844,100
Total	730.920	954,220	1,685,140

[Source : reworked from GHS, 1984, Hospital Services Inpatient Stays p. 135 Table 8.9 and Population and Vital Statistics , Health and Personal Social Services, 1986.]

Table 5 demonstrates that between 1973 and 1984 there has been a 10% increase in hospital throughput. In every year more women than men are hospitalised, regardless of age. Although the elderly constitute a growing percentage of hospital inpatients , patients between the ages 45-64 alone comprise nearly one half the total number of inpatients. This

represents a substantial number of patients who potentially require special care and assistance in the community and are not currently recognised by community care policy.

The Oxford Regional data on the Milton Keynes District Hospital indicates that for General Medicine and Surgical wards alone, in the six months between January and June 1986, a total of 3,368 patients were discharged [ORHA Discharge Data, 1986] . In total Milton Keynes District General Hospital recorded 17,147 discharges and deaths. [Source: Dept. of Community Medicine, District Information Unit, Quarterly Information, Jan.- March 1986, April - June 1986, July -Sept. 1986, Oct. - Dec. 1986]

A consideration of the MKDH inpatients indicates that the economically active age group utilizes the beds in numbers equal to or greater than the elderly. It also demonstrates that males are represented in all age groups in greater numbers. In terms of the total number of patients seen , surgical wards have a higher throughput and shorter lengths of stay than general medical wards. Surgery patients are also younger than general medical patients, with the 15 -44 year old age group and the 45-64 year old age groups being the most represented .

Table 6. Milton Keynes Hospital Inpatients ,General Medicine and Surgery, January to June 1986.

General Medicine: January to June, 1986

	1-14	15-44	45-64	65-74	75+	Total
Females	9	278	162	152	188	796
Males	30	234	257	194	146	868
Total	39	512	419	346	334	1664

Surgery: January to June, 1986

	1-14	15-44	45-64	65-74	75+	Total
Females	66	408	216	95	100	750
Males	220	447	273	175	133	1254
Total	286	855	489	270	233	2004

[Source; ORHA data ,on MKDH, Hospital Activity, January - June 1986]

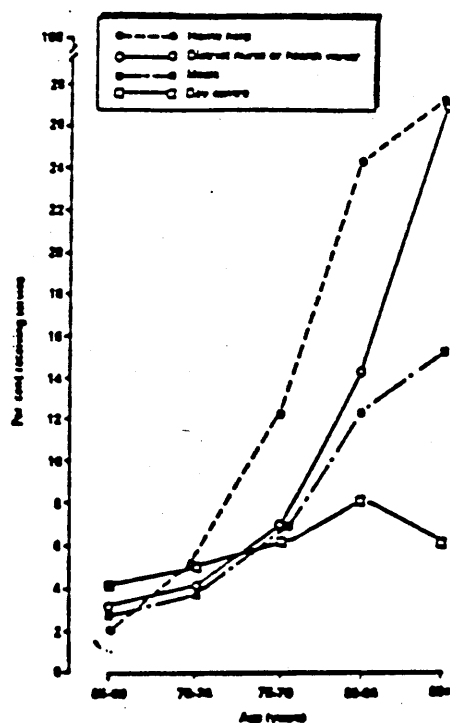
The analysis of these hospital inpatients indicates that it reflects the morbidity and mortality pattern documented in the General Household Survey data. It therefore, provides some new data. The data collected on NHS hospital inpatients does not include data on social class and inpatients, although it does so for the private hospital utilisation.

A. Community Statutory Provision

The document Priorities for Health and Social Services [DHSS, 1976] and Care in Action [DHSS,1981] recommended increased levels of social service provision such as home help, and meals on wheels. The recommended levels of statutory provision are 12 home helps per 1000, for the over 65's. It is therefore based on an age structure and does not reflect a broader base of need. Nationally, these policies, affect a large number of people in the priority groups. Among those 65 and older, about one million are receiving care and another one-half a million people under the age of 65 , physically or mentally handicapped are receiving care. Between 1976 and 1983 the prime community services for the elderly, home helps, meals on wheels and day care places, grew by 10.8% , 0.5% and 27% . Only day care places kept up with the 13.3% growth of the over 75's. [Baldock,J., 1986]

The work of Grundy [Grundy,E., 1987] , shows that while the services are increasing it is uneven in the respective types of provision and that services are primarily aimed at the over 75's [Figure 2]. Despite the increase in staff, the findings of Grundy and the Audit Commission suggest that the number of cases is exceeding supply of domiciliary and professional workers.

Figure 2. The Proportion of People in Receipt of Services, Meals on Wheels, Home Help, or visit by a District Nurse or Health Visitor



Source: General Household Survey, 1980 and in Grundy, E. 1987

The concurrent practices of increased hospital expenditure and staffing, increased hospital throughput, earlier discharge and an allocation of social service support directed primarily at the very elderly, means that it is less likely that younger age groups will receive support in the community. This is despite the fact that morbidity and in-patient data indicate "that class differences are a constant feature over the entire life span.... At any age people in occupational class V have a higher rate of death than their

better off counter parts" [Townsend,P. and Davidson,N, 1980,p. 51]. The General Household Survey on morbidity shows parallels to mortality data. For example, the morbidity data shows that absence from work is strongly related to social class. The average number of days lost through illness or accident among unskilled manual men was 4.5 times that of professional men in 1971 and 1972. [Townsend and Davidson, 1982].

III. The Case for Acute Care

The analysis of the policies and the data suggest that there are a number of compelling reasons that the nature and scope of the CCP needs to be extended. First, it has to be recognised that the community care policy has been transferring large numbers of patients from acute care wards earlier into the community. Thus in reality, both long stay and short stay patients are being discharged into the community. The lack of growth of the community sector of the NHS, the focus of social service support on the very elderly, the slow growth in the numbers of general practitioners [Table 2], combined with the slow growth of joint funding raises concerns for the care of acute convalescent patients. The 'double number' of long stay patients and short stay patients being rapidly discharged into the community potentially places increased demands on already limited

resources and limited services. Thus, the reality is that financing and professional services are not matching the discharge of patients. Furthermore, the Community care policy is directed at specific client groups, and this does not take into account the fact that morbidity, and more specifically acute ill health, increases with declining social class. The fact that the CCP and PHSS were directed at the priority groups is also reflected in the fact that community care funding is not related to the social and demographic characteristics, but primarily to the numbers of elderly, disabled or mentally ill. The fact that acute ill health affects people in all stages of the life cycle, and in different occupational classes means that informal and formal caregiving is needed across as well as within particular population groups.

As the report Care in Action [DHSS,1981] states " Community Care in relation to specific client groups has been the subject of considerable attention but much less effort has been devoted to an overall analysis of the development of community care." [DHSS, 1981, p. 25] Indeed, the Care in Action report notes that 'early discharge schemes require adequate district nursing support and "such schemes should not be introduced without full consideration of the workload of district nursing teams." [Care in Action, 1981, p.49] The work of Amos [Amos,G. 1973], Urquhart [Age Concern,1975] and Skeet

[Skeet,M., 1982], while primarily concerned with the discharge of the elderly from short stay hospitals, expresses concern about the disparity between need and receipt of services in convalescent community care. This work confirms Walker's statement that "there has been no sustained attempt to define and measure the need for community care to set policy goals and then to relate the goals to the scale of need and the allocation of resources" [Walker,A. 1982, p.16]. It is apparent from the policies and the data that there is a sea of changing need in community care [Baldock,J., 1986].

A. Theoretical and Practical Issues for the Study of Acute Care

The research raises both theoretical and practical issues which are central to health and social policy. This is due to the fact that the 'problem' of acute ill health is rooted in social and political institutions ,and in the decisions about public expenditure, as much as it is a result of biological changes and individual action.

The 'problem' of acute ill health centralises at a conceptual and theoretical level the relative importance of individual actions, and social structural forces. It brings together the debates on social and medical models of health . It focuses

attention on the role and responsibility of the state and the responsibility of the individual. The move away from both institutional and professional care to community care for acute convalescent patients, raises questions about the differences in lay and professional care as well as about the nature and availability of informal and formal caregiving in the community. Finally, it raises the question of viewing health and ill health as an issue throughout the lifecycle, between the economically active and retired, and men and women.

The examination of health and social policy in recent years underlines the government's increasing belief in the role and responsibility of the individual for health care, particularly in the case of acute ill health. This has been implemented through government cutbacks per capita, per in-patient and in the community. The decreasing role of the state concomitantly places an increasing responsibility on the individual and the family to be 'providers, negotiators and mediators of health care'[Graham,H. 1979]. The philosophy implicitly assumes a behavioral explanation for acute ill health .It therefore tends to emphasize the role of individual lifestyle behavior for incurring ill health. However, the data on morbidity and mortality cogently points to the strong association between broader social factors in ill health, based primarily on direct or indirect economic forces. An alternative explanation

of ill health, presents health and ill health as an interaction of social structural forces, individual biography and a persons biological state. [Davey,B., 1985, p.223] Biological changes, for example, occur, as we grow up and grow old, and they are bound up with social phenomena, such as economic circumstances, education, un/employment/ retirement, and personal life events , such as marriage, divorce, parenthood, and bereavement. The view put forward by Davey, conceptualises ill health as a transitory or permanent state which is related to both individual actions and economic , political and social forces. Thus , community care becomes, not simply , care for specific priority groups but, for all patients, in all stages of the life cycle.

In terms of the 'triangle of responsibility' for health care in the community, the problem of acute ill health raises the issue of the relationship between the hospital ,and community professional medical and social services to discharged patients. Given the limited resources for community care , it becomes important to study who receives statutory care in the community, how it is obtained and what is needed by convalescent patients. The issue of earlier discharge and lack of statutory recognition of acute convalescent care raises the specific problem of what the family is able, willing and could contribute to convalescent care.It focuses the debate between the role of professional medical care and lay care and on the

relationship between need and the receipt of services , as well as the nature , type and timing of services.

There are a number of compelling reasons for conducting small scale research on acute care based on a district hospital. Given the limited amount of research on acute care and hospital discharge into the community it is necessary to undertake small scale research on a local basis which is sensitive to the issues in a particular locality and the needs of individual patients. Furthermore, given the increasing trend in health and social service policy and in statutory health and social service personnel to be based on particular localities it is important to evaluate the implementation of these policies on a 'community' basis. Finally, statistical data can not be informative without the meanings , interpretations and beliefs which people attribute to their daily lives.

Chapter 2

Issues in Community Care

This chapter examines the reality of community care. The fact that the priority groups and convalescent patients are being discharged into the community earlier, combined with lower real, NHS expenditure raises concern over the growth in community statutory provision. It addresses the current issues and problems in community care and identifies the reasons why research on acute care in the community is needed. The definitions, the assumptions, and the implementation of the Community Care policy, as it has affected the 'priority groups', is examined. This literature review pinpoints the issues of community care for the mentally ill, the elderly and the handicapped. It presents an analysis of the nature of the 'priority groups', 'what' the social and economic implications are for the family, and the relationship between the family and statutory services. Finally, the analysis of the priority groups raises important questions about the needs and the after care of acute care patients in the community.

I. The Definitions and Assumptions of Community Care

A. Definitions of Community care

In recent years the DHSS, Health Authorities, and social scientists have attempted to define what is meant by community care. An examination of a few of the definitions demonstrates that there are common themes which form the basis of the conceptualisation of community care. These general definitions have provided the format for the implementation of community care. The themes which these definitions share in common are an emphasis on family care, provided by lay carers for homogeneous groups of people, in non-institutional settings.

In 1981, Care in Action [DHSS, 1981] defined the term "community care" as the "shift in balance of care away from long term hospital or residential provision for certain people whose needs put them on the boundary between institutional and other modes of care." [DHSS, 1981, p.46] Similarly, the Milton Keynes Health Authority Strategic Plan states that " the Region aims to become more 'people' oriented ' than 'institution oriented' with growth in health care staffing occurring predominantly in the Community over the next ten years" [MKDHA, 1986].

Alan Walker defined community care as the provision of help

and support to individuals, people with disabilities and elderly people in non-institutional settings; such care may be provided by informal, quasi-formal or formal helpers or a combination of all three [Walker,A. 1982, p.5].

The appeal of community care has been embedded in notions of warm and caring social networks with family and friends. This conceptualisation is in stark contrast to the perception of institutional care as 'batch living' and 'segregated inmate worlds' [Goffman,E. 1961]. A consequence of defining community care as primarily a move away from institutional care, has resulted in an inadequate understanding of 'for whom' the care is to be provided, or who would provide the care and what it's cost would be for families. The definitions treat the 'priority groups' as homogeneous groups, without recognising an institutional and structural basis for the nature of the 'priority groups'. It has failed to recognise that for many people ill health is a 'career' which is linked with material and social circumstances. Furthermore, because the emphasis of the definitions is on the transfer of care from institutional settings to the home, there has been little recognition that community care is also a move away from professional care. Thus the transfer of care from 'institutional settings' to the community is about both a change in where care is provided , who provides it and the nature of that care. The definitions therefore make

assumptions about the nature, availability and ability of the family, friends and neighbors ,in the community , to provide care.

B. The Assumptions of Community Care:

B.1. Assumptions about the Priority Groups:

The definitions of community care have emphasized the transfer from hospitals and similar institutions to homes and day care centers. This has occurred without an adequate understanding of 'for whom' the care was to be provided. As a result there has been an emphasis on the homogeneity of the 'priority groups'. The tendency has been to perceive the elderly, the mentally handicapped and the disabled as a single group, when in practice they are a heterogeneous group, with different origins , causes, social and economic circumstances.

Abrams, [Abrams,P. and Brown,R., 1987] for example, argues that the debate about the 'social problem' of the elderly , is based on the biological characteristics and demographic changes. In fact , he argues, "what is obscured is that the problem of dependency in old age is also socially created - by the family, as a social institution, retirement as an economic institution and pensions as a political institution.

In each case, the particular sorts of institutions help in turn to construct the problem of the elderly." [Abrams,P. ed. 1986] Similarly, Graham [Graham,P. 1987] has argued , old age is a socially constructed dependency, which is characterized by 'role exits', which are assigned on the basis of biological age. Therefore what the elderly have in common is their relationship to certain structural aspects of society. Retirement and a decline of income is the central feature of the 'elderly'. However, poverty and material comfort in retirement, among the elderly, is usually related to employment and unemployment during the working life. Indeed, Townsend and Davidson, [Townsend,P. and Davidson,N. 1982] concluded that social class is a more important variable affecting health status than age. They found that the national data demonstrated that retired professional elderly have better health than the lower social class economically active worker. The emphasis on ill health with increasing biological age therefore ignores the class differences in morbidity and mortality [Central Statistical Office, Social Trends, 1985]. Access to goods and services , standards of housing, community resources, diet and of the ability to remain warm and well clothed are all determined by the relation to the labour market during the economically active years. The experience of 'old age' is therefore tied to one's former position in the labour market.

In contrast, mental illness is particularly associated with low income families, poor housing, unemployment and the lack of a 'significant other'. [Brown,G., 1978] It affects people mainly in their adult years and it may be a short or long term problem. What is termed as mental illness may range from normal sadness through deep gloom, to mute withdrawal and psychological pathologies. It is not always easy to distinguish between what may be a normal, if severe, reaction to adversity and what might be a pathological degree of distress. In practice depressive types of illness are often associated with or preceded by some event involving a deep sense of loss. The death of a spouse, the break up of a marriage, the damage to self confidence that a disabling illness or mutilating accident can have, are often forerunners of depression. Brown argues that the type of depression does not matter, but that depression is usually associated with particular provoking agents, or 'vulnerablility factors', and that these explain the differences in social class experience of poor mental health. The working class encounter more untoward life events and encounter more depressive illness. Brown's work, therefore suggests that there is a social and structural basis to mental ill health [Brown,G.,1978].

In contrast, physically and mentally handicapped children, may require life long support, depending on the level of severity. They may remain perpetual children , dependent on

someone for personal care, social support and financial support. Bayley [Bayley, M.J. 1982] distinguishes between the mildly subnormal and the severely subnormal and the demands placed on the family depending on the level of severity. Bayley found that the parents of the severely subnormal are evenly distributed among all social strata in the society. The mildly subnormal, on the other hand, come predominantly from the lower social classes. The mildly subnormal are substantially under represented in the professional group, significantly under represented in the intermediate and skilled groups and they are over represented in the unskilled group. Bayley goes on to question whether it is a fact that the severely subnormal are actually evenly represented in all social classes or whether changes in the social class structure have actually obscured the extent of the problem of the severely subnormal in the lower occupational classes. What is certain is that the over representation of the mildly subnormal among the lower social classes suggests that social and economic circumstances contribute to the problems associated with physical and mental handicap.

We can therefore see that there are a multiplicity of characteristics both within each of the priority groups and between the priority groups and that the relationship between the origins, causes and outcomes are different. The process of becoming elderly is based on biological changes ,but

interpreted and reinforced by social institutions, the mentally ill are associated with physiological and social 'provoking agents' and the subnormal and physically handicapped are a result of birth defects or accidents. The cause of the 'problem' of the elderly, the mentally ill and the mentally and physically handicapped has as much to do with the structural factors as with biological or physiological circumstances. Economic and social inequality form the basis for the problems shared by many of the priority groups. Where the priority groups differ between each other and within each group is due to the degree of physical, emotional or practical dependency, the degree of financial well being, the stage in the life cycle, and the relationship of the dependent person to the carers.

B.2. Assumptions about the Shift of Institutional Care to Community Care:

A central assumption of the community care policy, which is reflected in its definition is that community care represents a move away from institutional care to care 'at home', surrounded by a close family network. What this conceptualisation has obscured is that community care is also a move away from professional care to lay, family care. More specifically, it is a move away from the centralisation of resources and professional expertise to the differentiated material and social life of lay care. It is a move from 'batch

living' to private living, and it is a move from impersonal, secondary relationships to personal, family relationships. It also represents a move from professional norms of caring; ideas based on medicine and science, experience and authority [Freidson,E. ,1970] to lay notions of caring, which are differentiated by family, class and education [Suchman,E.,1965; and Blaxter,M. and Paterson,L. 1982; Calnan,M. 1987] . Therefore, there is a greater variety of conceptions of the causes of health and illness as well as strategies of care management. Lay health knowledge is based on general knowledge, accumulated in an informal manner, which lacks specialisation, experience and authority.

B.3 Assumptions about the Nature of the Community

The definitions of community care are based on a number of assumptions about the nature and availability of the family, and the 'community', throughout the life cycle. It has made assumptions about the social and demographic characteristics of the population, and it has made assumptions about the structure of the family and role relationships within it. However, questions have increasingly been raised about the 'ability ' of the community to care because of current trends in the family structure, employment, and the changing demographic structure of Great Britain.

The community care policy, assumes that family care for the physical and emotional needs of the elderly, handicapped and mentally ill is better than institutional care. In making this assumption, the community health care policy makes specific assumptions about the nature of the community, and about the nature, composition and availability of the family. Specifically, the policy assumes a 'model' of the family which is ; " a stable family with the woman at home, supported financially by her husband at work caring for an elderly relative who lives with , or near, the nuclear family unit." [Wicks,M. 1982, p.107] The concept of community conjures up images of rural, caring , moral communities bound by obligations, both culturally and legally. It is associated with attachments grounded in a locality, which are characterized by, personal intimacy, emotional depth, moral commitment, social cohesion and continuity in time [Abrams,P.,1987]. The Community Care Policy therefore makes demographic and structural assumptions about the nature of the family and about geographical localities. An examination of these assumptions produces evidence which suggests that the 'community' is not entirely congruent with this , and that there are important problems with this conception.

Although, the family is the prime caregiver, [Wicks,M. 1982 p.103.] divorce, marriage , employment patterns and geographical mobility all affect the ability and availability

of the family to provide care. The increasing trend in divorce has had a significant impact on the numbers of adults living on their own. The pivotal role of spouses in providing care means that divorced people are more isolated and more financially vulnerable as a result of ill health. Divorce also has had an impact on the availability of "children" to provide care for their elderly parents. Wicks points out that much of the current literature on divorce focuses on the effect of divorce on children, however it is also of increasing significance to the provision of care for the elderly.

An examination of national demographic data [OPCS,1984] indicates that in each age group there are significant numbers who are single. For example, among the 25 -34 age group 20.9% of females and 34% of males are 'single', whether this is due to bachelorhood, widowhood or divorce. With increasing age, widowhood becomes the prime factor in being single. Among the 45-59, widowhood becomes the prime factor in being 'single' for women; for men this does not occur until age 65 and over. These statistics suggest that there are a high percentage of people, particularly women, in their older adult years without a spouse to provide care.

Changing employment trends and rising unemployment are also factors which affect 'who' is available to provide care.

The changing role of women in the family and in the labour

force has affected the decisions women and the family make in caring for relatives. The percentage of women in the work force has increased from 21.5 % in 1951 to 46.3 % in 1966 and to 61% in 1979 [Rimmer,L. and Popay,J., 1982]. The General Household Survey 1984 found that three-fifths of married women under retirement age are economically active [OPCS,GHS, 1984] This would suggest that the 'pool of available caregivers' [Moroney, R.M.,1976] may have declined as a result of women's increasing role in the labour market. However, it is the case that men still earn 1 1/2 to 2 times as much as women. Almost 1/2 of all full time women earn less than 100 pounds per week and that overtime pay for men is 3 - 6 times as much as women. [CSO, Regional Trends, 1985] Furthermore , women still constitute the majority of the workers in part time jobs ,which are low paid and have no security or employment benefits. Thus, women's net contribution to the family household income is lower.

The increased unemployment rate in Britain is of concern because unemployment affects both who is available to provide care and the material resources of the family to provide that care. Unemployed families have the time to provide care but not the resources. The unemployment rate has increased ,in recent years, from 3% in 1971 to 13% in the year ending mid 1983 [Central Statistical Office, Social Trends, 1984-1985]. The increasing unemployment has also had an effect on women's

economic activity. The evidence to date suggests that wives of unemployed men, usually give up work too, due to the 'earnings rule' on supplementary benefit. [Rimmer,L.,1981.]

The provision of care, however, is not only dependent on economic security but also on the geographical proximity of family members. [Wicks,M. 1982, and Bulmer,M. 1987] Greater geographical distances between family members effects the ability of family members to perform tasks on a daily basis. Being within five minutes reach, seems to be a critical time in the willingness to provide care. Hunt's earlier study of elderly people had found, for example, that a significant proportion [48%] were living at a distance of greater than 6 miles and this reduced contact with carers [Hunt,A.,1978] There is concern that the increased dispersal of the extended family has meant greater isolation for the people who are ill and for the elderly.

B.4. The Demographic Structure

The changing demographic structure has generated concern over the care for the increasing number of very elderly people. The literature in recent years has focused on the 'burden' of this growing section of the population due to the anticipated demands they will make on health and social service

resources.[Abrams,P. and Brown,R.,1987., Grundy,E., 1987]

A look at Table 7 shows that the largest population increase is in the 15-44 year age group and in the 75 + age group. There is however a slight decline in the numbers of people in the 45 - 64 year age group, between 1973 and 1983. The table also shows that the population in the economically active age group [15 -44 and 45- 64] comprises the largest percentage of the population; and are almost double the rest of the population. Indeed, those in the over 65 year old age group only comprise approximately 15 percent of the total population. Thus , although the very elderly are increasing in numbers , their percentage of the total population is relatively small. In actual fact, it is the large number of people [in absolute numbers] in the 45-64 year old age group, who take up 55% of all [acute] hospital beds [Audit Commission, 1986], who should also be of concern.

In summary, a closer look at the social statistics confirms a more diverse community than is assumed within the community care policy. The current concern over the numbers of the elderly, although of significance, must not obscure the large numbers of people in the economically active age group who are hospitalised.

Table 7. Population of England by Age, 1973 - 1983

Persons	1973	1980	1983	1983 %	1973-1983
	[thousands]			of pop.	% change
All Ages	46,686	46,787	46,846		
Under 1	650	602	588	1.2	-.1
1 - 4	2,881	2,184	2,355	5.0	-1.1
5 - 14	7,481	6,906	6,221	13.2	-2.8
15 - 44	18,188	19,587	20,159	43.0	4.1
45 - 64	11,061	10,441	10,462	22.3	-1.3
65 - 74	4,126	4,374	4,153	8.8	0
75 and over	2,294	2,693	2,908	6.2	1.3

[Source: OPCS, Health and Personal Social Services, 1986 Population and Vital Statistics , Table 1.1]

The heterogeneity of family households , due to divorce, widowhood unemployment, women's increasing participation in the workforce constitute a significant divergence from the 'norm'. These factors cast doubt on the homogeneity of 'the family' upon which the community care policy predicates itself. The assumptions of material comfort which the community care policy makes , belies reality for most families who are caring for an elderly relative, the mentally ill or the physically or mentally handicapped. If economic hardship is understood within the context of the social and economic relationship to the distribution of disability and handicap, then the 'problem' of care in the community becomes

potentially more acute. Finally, the concern over the changing demographic structure should not obscure the distribution of ill health in the population as a whole.

II. Implementation of Community Care

Who Cares in the Community? The Family, Neighbors and Statutory Services.

Attention in the literature on the implementation of the community care policy has focused on 'who' provides 'Community Care', 'what' they provide, 'how' adequate is the care provided and what are the social and economic costs for carers? There is concern about the implications of a shifting balance in the 'triangle of care' between the state, the community and the family.

A. Informal Care: The Family

Abrams's argues that " Social policy for it's part, having just begun to shift its attention from the idea of institutional care to that of domiciliary care, is now being called upon to make a further move away from concentrating 'care' on a particular age group; and towards protecting and enhancing the family as a setting for relationships of reciprocity throughout the life cycle" [Abrams P.and

Brown,R.,1986, p.14].

The literature on community care provides overwhelming evidence that the family does play a vital and active role in the care of dependent children, parents and spouses. Care is provided principally within the nuclear family but also inter-generationally and caring, as an activity, continues throughout the life cycle. Spouses tend to be the prime carers for each other. Care is also often provided by daughters for their elderly parents, by mothers for their disabled children and less frequently care is provided between siblings. Graham [Graham,H.,1983, p.23] argues that "the family unit provides the structure in which caring is carried out; in which children are nurtured, husbands sustained and the elderly and handicapped supported". Indeed, much of the literature , which over recent years has argued the 'decline' of the family as a fundamental social institution, bares little resemblance to the evidence. The family remains the most valued social relationship based on solidarity, reciprocity and attachment

Parker's [Parker,G., 1986] review of the literature on informal caregiving, supports Litman's [Litman,T.,1971] conclusion; 'that the family constitutes the most important social context within which illness occurs and is resolved.'

This suggests that there are strong normative and cultural imperatives governing caring behavior for the family throughout the life cycle. Caring by family members occurs through the generations for elderly parents and for

children, and inter-generationally, primarily between spouses.

Care between spouses [Oliver, J. 1983 ; Ungerson, C. 1987] is the most strictly interpreted and socially prescribed caring relationship. She argues that while " most carers did not have a choice about taking on their caring commitment, spouses can be seen to have the least choice of all" [Oliver, J. 1983, p.73]. Marriage and marriage vows, in particular, offer a unique relationship of mutual aid based upon an intricate network of dependencies, especially for women [Land, H. and Parker, R.A., 1978]. The evidence is that women give up work reduce the number of work hours or alter the type of work in order to care for dependent spouses. Furthermore the longer longevity of women means that they are more likely to provide care for their spouses during their lifetime.

There is overwhelming evidence that women provide the bulk of the care. Studies of the elderly, and physically or mentally handicapped children all indicate the centrality of women. Hunt's [Hunt, A., 1978] study of old people at home, for example, found that daughters and daughters-in-law were more likely to be helping elderly people with household and other tasks than were sons and sons-in-law. Nissel and Bonnerjea's [Nissel, M. and Bonnerjea, L., 1982] study also found that daughters were, in particular, the most likely to take on the burden of responsibility for their elderly parents. Once the

relative was settled with one of his/her "children", other relatives contributed very little. Parker argues that 'the evidence' then, is unequivocal. While the family, where it exists, still cares for its elderly members within the family, it is wives, daughters, daughters in law and other female relatives who shoulder the main burden of the responsibility." [Parker,G. 1985, p. 129]. The most recent data available in "Women and Employment Survey" [EOC, 1984] found that 13% of all women, between 16 and 59, had caring responsibilities for sick or elderly dependents and most of these people could not get by without the support of the caring family.

Studies of disabled children, similarly, reveal greater responsibility falling on women. Wilkin's [Wilkin,D.,1979] study of mentally handicapped children, found that mothers did the bulk of the caring for their children and that "the father's role varied little from the dominant cultural pattern." Similarly, Glenndinning's [Baldwin,S. and Genndinning, C.,1981] study of seventeen severely handicapped children found that the increased hours of care required for very dependent children made it very much less likely for mothers to take on employment despite the desire to do so.

What is evident from the research is that the family , and women in particular act as a carer throughout the life cycle. Ungerson draws a life cycle typology to illustrate the social

,economic and ideological factors which are influential in determining why women are carers throughout their life cycle [Ungerson,C., 1987]. The different stages of the life cycle share particular characteristics which are associated with different economic and social commitments. The procreative, nurturing and years of dispersion, the so called 'natural phases of the life cycle', provide a more or less stable basis for the social division of labour, power, privilege and identity" [Abrams, P.and Brown,R., 1987, p.10] Each of these stages of the life cycle has its own particular constraints in providing care. For example, studies of caring for physically or mentally handicapped children have consistently demonstrated that mothers spend greater amounts of time caring for the young and the fact that husbands need to work longer hours in order to provide for their families [Baldwin,S. and Glendinning,C., 1981]. During the child rearing phase of the life cycle women usually give up employment. The social obligations of 'grown daughters' caring for the elderly are in a different nexus of relationships. A consideration of female employment data, shows that women return to work at about the same time as they begin to care for elderly parents. It is roughly at this same time as children are leaving their home. Fay Wright's study, for example, of single carers , demonstrated the preponderance of women to take on a caring role for elderly parents even if this meant giving up work. Indeed

approximately one half of the women in her study gave up work in order to look after their elderly parent [Wright,F.,1983]. The concern is that for these very women who have spent a life time caring for others , with little or no pensions due to lack of participation in employment, they may become the most vulnerable and dependent in old age. This trend is confirmed by the statistics. In 1979 , 1.2 million women over pension age were receiving supplementary benefit, [ie. 72% of elderly recipients], although women made up only two thirds of all people over retirement age in 1979. [Wright,F., 1983]

Contrasting mortality rates for men and women affect caring relationships in the latter part of the life cycle. The statistics produced in Social Trends 1982-1983 show that 74% of all men over the age of 65 lived with their spouse, Among women, only 34% lived with their spouse over the age of 65. The small number of women living with their spouse over the age of sixty -five reflects the earlier and higher mortality for men. There is a concomitant increase in the number of women living with other family members. Sixteen percent of women over the age of 65 live with their own children or other relatives, while for men this percentage decreases to 8%. This would suggest that during a woman's lifetime looking after her husband, children and elderly parents that she will in turn be more likely to be cared for by her own children, particularly her daughters.

A.1. Women as Carers:

Explanations for the predominance of women as carers have focused on ideological, cultural, and economic explanations. These forces are a part of the process of women's socialisation, a part of the biological and social role created and sustained by the family, and a part of social and economic policy. It is the interaction between the individual and the society which shape and determine women's caring role. At the level of the individual, socialisation patterns and individual life experiences, and observations serve to create models of girls, mothers, wives and daughters in caring roles. At the level of society, Clare Ungerson speculates in "Why do Women Care" [Ungerson,C.,1983] that women more than men predominate amongst informal carers because there are powerful material and ideological forces that determine their roles.

Seeking to explain girls behavior and what they have in common as a group ,Gilligan's [Gilligan,C., 1982] study of socialisation patterns identifies different orientations between boys and girls. She found that girls develop a personal and relational orientation, whereas boys develop a positional and rights orientation. Gilligan found that girls were less rule bound and more innovative in their attempts to create social harmony. Gilligan argues that women, as a

result, develop a care orientation. They evaluate themselves in terms of their ability to care, and how effectively they can maintain relationships and their responsibilities. She found that the consensus of women's perception of themselves is as carers and nurturers. A result of this is that women are particularly vulnerable to being made to feel guilty in any circumstances, and caring is an area where this vulnerability can be most played upon. Gilhooly [Gilhooly, M. 1982], for example, found that the expectations among family members influenced who cared... 'when both sons and daughters were potentially available to give assistance, sons were rarely expected to give as much help as daughters. This supports Graham's argument that caring is both an identity and an activity [Graham, H. 1983, p.14]. Women come to perceive themselves and fulfill a role as carer as mothers, daughters and wives. These ideological forces not only act to convince women of their role in the family and in society but they are also implicit in social policies which rely directly or indirectly on their labour.

The economic factors which explain why women care more than men are related to women's place in the economic structure. As it was indicated earlier, in the last twenty years, women have become a large part of the labour force. In half of all married couples under retirement age both husband and wife are earners and on average women earn 25% of the family

income.[Central Statistical Office, Regional Trends, 1985]. As a result of their combined roles in the family and the labour force, women are more likely to work part time . Furthermore, because women are perceived as being less committed to work, it is assumed that the 'opportunity costs' of career options are less for a woman. Therefore women are at one and the same time forced to move in and out of the labour market because of the perception of their role and because of their unequal relationship to the economic structure. Finally, because women circulate in and out of the labour market during periods of child rearing and care for other dependents they loose their 'career progression'. The overall affect is that women make a smaller net contribution to the family and the smaller direct cost and indirect cost to the family creates the situation that women are more likely to provide care.

Ungerson, however, has argued that it is not only women's position within the employment structure which explains why women care more than men, rather it is also because " social security policies play a central part in maintaining an ideology of the nature of family life and the particular roles within families that men and women should play". [Ungerson,C. 1983,p. 41] Land [Land, H.,1978] also has argued that the community care policy while not appearing to be a policy counter productive to other social policies, is an ' implicit

family policy because it is based on certain assumptions about the nature of relationships between the sexes and the generations" [Land,H.,1978, p.257] The evidence is that the CCP, in fact, places women in a position to provide private domestic care. It has been argued by Land that the social security system also reinforces the trend in the labour market and it places additional forces on women to stay in the traditional female role. It is based on the concept of one male breadwinner upon whom the rest of the family relies. The importance of the wife's contribution to family income is ignored. For example, the Invalid Care Allowance until recently was payable only to relatives, who are of working age, who stay at home to care for a disabled person, and not to wives. It therefore had been a very gender specific type of welfare provision, which reinforced the subordinate and dependent role of women. In 1986, this ICA legislation changed, and it is now available to married women. This is , of course, a real benefit to carers. However, the financial contribution of these benefits are low and they therefore primarily appeal predominantly to those on very low incomes. Indeed, the Audit Report showed that expenditure on the Invalid Care Allowance and the Attendance Allowance has levelled off [Audit Commission,1986]

For the least well off there are incentives for women to give up work if her husband becomes unemployed. The loss of

benefits which occur if she remains employed suggests that wives of chronically ill husbands, low income families, are more likely to give up, than take on employment. In contrast, the incentives to return or continue working are higher for professional employees.

In summary, social policies and fiscal policies therefore shape the kinds of decisions which women make. To quote Ungerson "Policy is Personal" [Ungerson, C., 1987]. These social policies embody and perpetuate women's perception of themselves and expectations in the family of their role. Thus, women's orientation for love and concern for others is relied upon in social policy. " The cultural definition of women as carers is still strong, and since it is a part of a set of assumptions about the sexual division of labour in the domestic sphere, it continues to be reinforced and reproduced by a whole range of social and financial policies which unquestionably embody the notion of women's dependency. What emerges from this is that it is necessary to recognize the interacting factors of inequality and the social division of labour and identity" [Ungerson, C. 1987].

B. Informal Care : Neighbors

The community care policy has also stated that neighbors are an important resource in community care. The work of Abrams [Bulmer,M., 1986] has focused on exploring the nature of neighboring as an important relationship which could be harnessed for the well being of dependent persons. Neighboring schemes were suggested as a method of providing a bridge between statutory responsibility and informal care, to develop an 'interface' between informal and formal care. Abram's influential work sought to identify the basis of neighboring. He argued that informal care was distinguished by being 'personal, particularistic and unorganised.' It is rooted in personal relationships and not in a commitment to particular tasks. Formal care ,in contrast,is universalistic, carried out by people who are initially strangers, who have specific roles to perform and a hierarchy of accountability. [Bulmer,M. 1986,p.4]

The work of Abrams on informal caregiving demonstrates the important role of neighboring in community care , although it is limited in its scope. The national survey on neighboring found that neighbors were of great importance ,particularly in emergencies. While 87% of the sample said that they get on very well with most of or all their neighbors, but this gives very little insight into the quality or frequency of this contact. Furthermore, approximately, 10% of the elderly felt

that they were unable to ask any neighbors for help, and this was particularly true for the housebound or the bedfast respondents.

Abrams identified four bases to active informal care; altruism, tradition, status and reciprocity. He argued that the reciprocity was instrumental in the development of a caring relationship. It was Abrams's idea that more informal care could be developed if this principal could be unleashed. He argued that if these bases of informal caring could be unleashed neighborhood caring relationships could be established. Abrams found that specific circumstances were conducive to establishing neighboring relationships . These were the length of residence, proximity, age and stage in the life cycle. Social class was another important variable , but it interacts with the other variables, its' effect is more difficult to interpret. Length of residence, however, was the most important foreground factor in terms of contact with neighbors and in terms of help exchanged. New settlements, whether working class or middle class, had more severe problems in fostering neighborhood ties.

The second most important foreground factor in accounting for neighboring is proximity. Consistently Abrams's research demonstrated that 'the people next door' were the most salient relationship, in terms of friendliness, help and reciprocity.

The relationship between age, stage in the life cycle and relationships of reciprocity was more ambiguous, in Abrams's study. In some instances reciprocity was well developed among those in the same stage of the life cycle, for example, among mothers with young children or among the elderly. Previously, Hunt's study had found that most elderly people were visited by neighbors and friends of the same age group. Among economically active couples, Abrams found, that neighboring ties were weaker. Women in employment did not have the time to promote contacts with those who lived nearby. Women, 'at home' were often pivotal in fostering neighborhood ties. This suggests that women's role within the family, as a carer, is continued in outside family relationships. That women play an instrumental role in organizing and establishing relationships of reciprocity within and outside the family.

The relationship between social class and neighboring is more complex. The comparisons of the different areas studied by Abrams contradicts the conceptualisation of earlier community studies [Stacey, M., 1960; Willmott, P. and Young, M. 1957] which emphasize working class reciprocity and aid. Abram's found that the old style of interdependence based on adversity was now gone. The comparison of classes suggests an inversion of the sociological stereotypes of the close knit, highly integrated working class community and the atomised,

privatised domestic world of the middle classes.

Bulmer [Bulmer,M.,1986] argued that it is the working class localities where modern conditions of neighboring prevail, and where there is a weak tradition of formal voluntary care organisations, which present the main challenge to Neighborhood Care Mobilisation. Among those helped by the neighboring schemes developed by Abrams et alia were primarily those in isolated areas which normally had support from relatives. However, it was found that the difficulty of implementing the neighboring schemes was that the volunteers were predominantly middle class and they were available to be called upon in precisely those areas where there was the least need, because the middle class had greater resources to overcome problems 'in daily living'. A major conclusion from Abrams's work is " that a commitment to reliable neighborly care cannot rely solely on voluntary effort [Bulmer,M., 1986, p. 204].

The inescapable conclusion is that there is a normative consensus on the role of the family to provide care. Neighbors are considered as a source of help, for particular types of assistance and for shorter periods of time. Assistance provided by neighbors tends to be rooted in attachment to persons and not the conscious performance of a role [Bulmer,M. 1986, p.4] The types of tasks which neighbors

perform appear to have a normative basis and are bound by unwritten rules. Neighbors perform specific tasks such as shopping, and generally do not become involved with personal forms of help, such as bathing. Given the variability in the factors which are conducive to neighboring; age, length of residence , stage in the life cycle and social class indicates a tenuous basis for community care. Furthermore the reliance by the state on 'reciprocity' in communities suggests a form of bartering; a bartering of time or other resources, in order for the reciprocal role relationship to be established. It is therefore based on a measure of equality of resources within the neighborhood. Families or individuals who have few resources are reluctant to ask for help because they are placed in a non reciprocal role relationship and this may partially account for the isolation experienced by many families.

C. Formal Care: Statutory Support

The Audit Commission most recently completed a comprehensive review of the implementation of the community care policy. It's general conclusion is that implementation has been slow and uneven. "Care in the community is far from being a reality in many places" [Audit Commission, 1986, p.5 & 6]. Specifically, it pointed to some common underlying problems;

a mismatch of resources to needs, organisational fragmentation, inadequate staffing arrangements and unintended consequences of social security policies. Nevertheless, the commission concluded that a successful introduction of the community care policy would result in enormous benefits, 'quite apart from value for money considerations ' [Audit Commission, 1986, p.65].

In order for the community care policy to be implemented effectively the Commission found a number of problems related to each of the priority groups. " In the case of the mentally ill there were twice the number of hospital discharges than day care places for them , and that no one knows what happens to people once they have been discharged" [Audit Commission, 1986, p.2]. Furthermore, the uneven distribution of local authority services, effects the elderly , particularly. In practice this means that the likelihood of people receiving help is as much dependent on where they live as on what they need. In addition, the Audit Commission found an overall reduction in NHS facilities and a growth in private sector residential homes. The growth of the private sector has had two implications for community care; one, is that those who can afford it may choose private care and secondly, that where some residents are entitled to receive help with their fees from supplementary benefit, they are not entitled to receive assistance for private domiciliary care.

The Audit Commission's findings confirmed the work of other studies. Grundy, for example, states " ironically, despite the governments stated commitment to community care, the chief growth area has been private institutional care. The number of day care places and sheltered housing units has increased in real terms, but the provision of domiciliary services, such as home help and health visitor visits to the elderly, has either fallen behind or barely matched the increase in the number of very old people." [Grundy,E. 1987, p.626] Furthermore , responsibility for the coordination of community based services is lacking. The Audit Commission found that " services are fragmented between a number of different agencies with different priorities, styles, structures and budgets, who must 'request co-operation from each other" [Audit Commission, 1986 p.7].

An analysis of the literature on the receipt of services for specific priority groups emphasises the task orientated nature of support services. The central conclusion from the review of the literature is that social services are provided in relation to the availability of family members or other relatives or friends. The studies indicate that if there is a woman available to provide care, the family is less likely to receive statutory support and services. The analysis of the

receipt of services by Parker, [Parker,G. 1985] and the studies by Bayley [Bayley,M., 1973], Hyman, [Hyman,M., 1977], Levin, [Levin, E., et al. 1983] all indicate that the receipt of services is intermittent, sporadic and primarily only reaches those most isolated or most severely in need. Gillian Parker's review of informal care [Parker,G. 1985] concluded that those who are very severely handicapped and live alone are more likely to receive statutory support, particularly in the case of the Home Help service and Meals on Wheels. Family circumstances had less influence over the allocation of community nursing services. Bayley found that in the case of disabled children , hospitalisation was the most likely outcome for families who had been receiving little or no statutory support. The study, The Extra Costs of the Disabled [Hyman,M., 1977], found that although 73% of the sample had seen their social worker in the previous year, the frequency of the visits varied from once to four times per year. Wheel chair users, who constituted 39% of the sample, had the benefit of a home help. However, in total, fewer men than women had this service because their wives or mothers were expected to cope with household chores.

Enid Levin [Levin,E., Sinclair,I., Gorbach,P., 1983] divided the types of statutory services into two categories; those which were 'intermittently provided but which had a major effect on the allocation of other services, such as general

practitioners, psychiatrists, geriatricians and social workers and those which were delivered on a regular weekly basis or involved in continuous episodes of direct care. However, in the past ten years there has been a decline of home visiting by general practitioners in England [Bucquet,D., Jarman,B. and White,P., 1985]. This is of central importance not only because of the care provided to patients by general practitioners, but also because general practitioners, act as gatekeepers to the provision of meals on wheels, home help and community nurses. The important study on 'Factors associated with home visiting in an inner London general practice' [Bucquet,D. et al.,1985] found that general practitioner home visiting varied in relation to sex, age, marital status, social class and distance from the surgery. The interesting results showed that the age distribution of home visits were highest in the youngest and oldest age groups, however men had more home visits than women. Men have a higher proportion of home visiting in all groups except for those aged 65-74 who are divorced or seperated and after the age of 75, whatever the marital state. Of the marital states, widowed men received the most home visits. Social class was an important variable in home visiting with social class I having more home visits than the other social classes. The highest number of home visits being made to social class I patients , living within the immediate area of the health center.

Levin's study focused on the relationship between nursing and domiciliary services and persons living alone or with others. She found that the provision of a community nurse was less likely to be given where the elderly person was living with others, was aged 80 years or more and had a diagnosis of dementia, was incontinent, had a serious physical illness or was showing signs of distress. Meals on wheels usually accompanied home help services although home help was sometimes given without meals on wheels. One or other of these services went to three quarters of the elderly persons living alone, approximately one half of those living with one other, and to only 15% where the person was living with two or more others. Thus, while Levin's study illustrates that help is provided where it is crucial, it also implies that many people need help and do not receive it.

A study which focuses on a specific medical diagnosis and the receipt of services, [Legh-Smith, J. , Wade, D. and Langton-Hewer, 1986] found that the most severely disabled ,stroke patients were more likely to have a district nurse. The major reason for the provision of a district nurse was for bathing. All of those patients living alone and needing help with feeding, dressing, bladder and mobility difficulties , or assessed as severely disabled received help. The chances of receiving assistance varied more with severity than with the availability of a carer. It was found that patients receiving

help whether living alone or with a carer , were more likely to be more disabled and more confused than those without help. In total, thirty-eight per cent of the sample living at home received one or more community services. However, after one year only 50% of the patients registered with the project were alive.

It could be concluded from these findings that community statutory care is temporary, sporadic and intermittent; depending on local demands, local coordination and local provision. The allocation of statutory domiciliary provision is given to those with severe disabilities, who live alone, are elderly and primarily in the case of severe need. It is provided primarily on a basis of 'crisis intervention' and reaches only the apex of need. Professional medical care, by general practitioners, is more closely associated to 'demand' by social class I, accessibility and the elderly. Thus leaving the men and women in the years in the 10 - 69 year age group responsible for reaching the health center, regardless of social class. Thus the majority of the caring responsibility falls on the family. To quote Melanie Henwood the "twin priorities of economy and rationalisation and the virtues of low cost solutions in the context of community care may simply mean a failure to calculate the personal, financial and social costs which fall upon the individual rather than institutions." [Henwood,M.,1986]

D. The Direct, Social and Opportunity Costs of Informal, Family Care:

Walker [Walker,A. 1982] points out that what is always counted as 'costs' are public expenditure and not private costs [DHSS,1981 and DHSS 1981 a]. It is therefore important for the literature on community care to document the direct costs, the social costs and the opportunity costs incurred by community care to the family. The direct costs refer to changes in income and expenditure patterns which are a result of providing care. Losing income or increased expenses, as a result of providing care, are examples of the most common types of direct costs experienced by carers. The social costs are concerned with the social, emotional and physical costs of caring. Carers often experience isolation and stress as a result of providing care and the impact on the health of carers is often high [Bayley,M.,1973; Levin,E. 1983 and Ungerson,C. 1987]. The opportunity costs, of providing care, refer to foregone employment opportunities as a result of caring responsibilities.

D.1. Direct Costs of Caring:

Studies which have investigated the direct financial costs of caring found that the effect on the family where the income is good there was minimum hardship [Baldwin,S. and Glendinning,C. 1981; Hyman,M., 1977]. In fact, Baldwin and Glendinning found that in those cases where the child's condition is stable and moderate, and services are good no effect may be noticed by the family. However, in low income families greater hardships were incurred and families experienced greater stress. Hyman's study on The Extra Costs of the Disabled, also found that the majority of disabled people incurred extra costs. The additional costs were for heating, laundry, diet and clothing and although, all the wheel chair users incurred extra costs, only 5% received benefits, the percentage contribution to the total extra cost varied enormously from 5% for heating to 64% for diet.

Baldwin's study found that most families developed coping strategies for financial problems posed by disablement. Some men increased their hours of work, while women tried to limit demands on their husbands time or energies. For many families ill health and disablement resulted in the need to make both immediate and long term economies. Immediate economies caused parents particular distress if they were recommended to provide a particular diet or extra heating and they could not afford it. Limited resources also were found to impose

restrictions on the number of meals out clothing, alcohol and social activities, as well as longer term holiday plans. Large items were also difficult to meet, such as repair and the running of the car. Telephones and cars make a substantial difference to the quality of life of disabled people and their families, because they enable the individual and the family to remain integrated with their family , friends and the community.

D.2. Social Costs of Caring for Dependent People

Studies repeatedly confirm that the prime costs of caring are the social and emotional costs [Bayley,M.J., 1982; Levin,E., et. al. 1983; Nissel,M. and Bonnerjea,L.,1982 ; Ungerson,C., 1987]. Carers describe their loneliness, isolation and despair. Carers face difficulties with competing hierarchies of obligations and responsibility. Often caring results in feelings of guilt towards family members, because normal 'role' relationships are not being fulfilled. Nissel and Bonnerjea found that in two -thirds of the families , caring for elderly people there was considerable tension. The provision of care often results in the lack of privacy and strained relationships with children and husbands. In addition to anxiety, physical and mental stress, often generated interpersonal conflict. Carers also often experience feelings

of guilt towards the dependent person because of their own feelings of inadequacy in being able to cope with practical, behavioral, interpersonal and social problems, which dependent people impose to varying degrees.

Levin's study of confused elderly people found that providing for routine practical help, dealing with interpersonal problems placed tremendous emotional and physical demands on carers. Indeed, where there are already existing weaknesses in family relationships they tend to become accentuated with the care for a dependent person.

Ungerson found different stresses and strains of caring in different stages of the life cycle. For example, women who wanted to go out to work or had to stop working in order to care for an elderly dependent. Other problems arise from the relationship in relation to the nature and type of assistance required by the dependent person as well as the level of contribution which can be expected from them. Ungerson cites instances where the dependent person is capable of contributing to preparing tea but are unwilling to do so.

Thus the contradiction within family care, is that precisely those for whom one feels the most love, duty and obligation, present such demands of caring, that carers may come to care

less for them. The root of this problem is in the relationship between caring 'for' and caring 'about' [Boswell,D., 1984]. The fact that caring for dependent persons is emotionally demanding and stressful and isolating is evident in the most common request from carers is for twenty-four hour home nursing care to provide relief from the continual demands of caring or some form of respite care [Oliver,J., 1983] .

D.3. Opportunity Costs

Opportunity costs refer to those costs which are a result of decisions which often have to be made between opportunities for promotion, employment or extra financial rewards, which are in conflict with the perceived needs of caring for a dependent person. As it was noted earlier about one half of the women in Wright's [Wright,F., 1983] study gave up work in order to provide care for a dependent person. For the majority of carers who leave work, this means not only a direct loss of income but that they are also unlikely to be able to return to a similar position later. For the women, in their forties and fifties, in Wright's study, giving up work meant both a substantial drop in current income in the size of the occupational pension and difficulty of being able to re enter employment at a future time.

The examination of the social and economic costs of caring conclusively demonstrate the need for concern over the disproportionate cost that some groups are required to pay. With the policy of government retrenchment in health and welfare policy how will families caring for the convalescent, mentally ill, handicapped and the elderly in their homes, likely to be able to cope in the 1980's?

III. Conclusion: The Problem of Acute Care in the Community

In conclusion, this chapter has presented an examination of the community care literature. This analysis has focused on the definitions, the assumptions and the implementation of community care for the elderly, the disabled and the handicapped. Specifically, the review presented an analysis of 'for whom' the community care policy was devised for, 'who' provides care for these dependents, the shifting balance of care from the state to the family and the social and economic costs of family care.

The literature review of community care raises questions of both a theoretical and practical nature concerning the shifting boundary between the hospital , the community and

the family. It raises questions about the conceptualisation of the community care policy and who statutory care should be directed towards and the adequacy of current statutory provision. It has been argued that in actual fact, both, priority groups are being discharged into the community from long stay institutions and patients are being discharged earlier from acute wards in district general hospitals. These issues are of particular importance because of the large numbers of patients discharged each week from district general hospitals. The economically active age group, alone, [Table 1] occupies 55% of all hospital beds [Audit Commission, 1986]. Current statutory community provision is directed towards the care of the elderly, the handicapped and the disabled to keep these people out of long term institutional care. The distinction of acute convalescent patients discharged from general medical and acute care wards is that they comprise patients of all ages who have been hospitalised for a short period of time for a specified disease. The already limited availability of statutory support for the priority groups suggests that additional numbers of care groups being discharged into the community places additional pressure on already limited community professionals and services.

In addition , existing community care policy is primarily directed towards the provision of social service support. In contrast, it has been argued that the discharge of acute patients into the community must consider not only the

availability of social service support but also the availability of general practitioners, and community nurses . In addition, it is important to identify the contact and the responsibility between the hospital, community professionals and the family. The fact that community care is primarily family care, it raises important questions about the transition from institutional care to home care and also from professional care to lay care.

Research has concentrated on the ability of disabled and elderly 'patients' to perform tasks in daily living, their age and family composition and the receipt of social services, particularly meals on wheels and home helps. This orientation neglects the ability of the family to cope with and implement medical care regimes. A patient discharged from an acute care ward is potentially both a 'patient' and a 'client' in the community. Thus, the study of acute care patients raises issues not only about the availability of the social services but also about the relationship between, and the availability of the hospital, community medical and social services and the family. The limited availability of social services and the sporadic nature of neighborhood support means that family care is isolated care. Indeed, the research suggests that family care is primarily 'women care'. Material, ideological and gender factors all interact to direct women into a caring role within the family. From this literature review and the

new questions it raises for acute convalescent care in the community supports Ungerson's conclusion that "Policy is Personal" [Ungerson,C., 1987]:

Chapter 3

Acute Care: A Marriage of Methodologies

"The sociological imagination enables us to grasp history and biography and the relations between the two within society. That is its task and its promise." [Mills, C.W., 1959, p.12]

This chapter on methodology seeks to place the current research on acute care in the broader context of sociological research design and research methods. It seeks to develop a recipe for the examination of acute after care in the community. This research must encompass both the structural factors which are associated with acute ill health and identify the private individual's ability and strategies of convalescent care management for both the elderly and the economically active patient. It seeks to establish a sound theoretical basis for research as well as a research design which evaluates the effect of social policies.

The first part of the chapter examines the nature of sociological research , the relationship between theory and method and the purpose of sociological research. The second part of the chapter presents a review of the particular

research methods in sociology used by a growing tradition of community care research, epidemiological research and research on inequalities in health. Comparing the uses of positivistic and humanistic philosophy and research methods it is argued that it is necessary to seek methodological marriages which ground the individual in particular localities and place him/her in a broader social context. Having set the stage, the research methods used in the study of acute care patients discharged from Milton Keynes District hospital are discussed. It is argued that research into acute care must follow the foregoing three research traditions because of its special relationship to structural features of society, and because the community care policy has distinctive implications for individuals. Thus the research in acute health care must span both a structural analysis and an ethnographic approach.

I Methodological Background in Health Care Research; The Nature of Sociology

The distinctiveness of sociological research is that at its very heart it is both a philosophical and a scientific discipline. It grapples with the fundamental tension between man and society [Bulmer, M., 1977]. It is concerned with at least two distinctive perspectives; 'Man' in society and with

man in 'Society'. In other words it is continually exposed to the dilemma of the individual's relationship to the structure of society and the effect of structure of society on the individual. Sociology is concerned with both structure and agency. To paraphrase C. Wright Mills , 'ordinary men do not possess the quality of mind essential to grasp the interplay of man and society, of biography and history, of self and world'.[Mills, C.W. 1959 p.10]

Historically sociology has investigated the nature of social action, social relationships and social structure and in so doing it has set itself the task of explaining particular problems in theoretically adequate ways. A consideration of the types of sociological research which has been conducted suggests a broad spectrum of research problems. There are three prime sources for sociological problems. One source of 'problems' for the sociologist arise from social problems , such as the early work of Rowntree. In this sense sociology addresses real problems in society. A second source of 'problems' originates from philosophical issues. It is concerned with concepts and the formation of concepts which do not have any operational meaning in reality but which act as powerful tools and heuristic devices to explore the nature of society. The examples of these concepts are ; alienation, community and status. Thirdly, sociological 'problems' are generated by other sociological research. For example, the

early work on community care raised the issue of care for the growing number of elderly and the problem of care for the carers.

These fundamental concerns of sociology have developed with different theoretical and methodological approaches and added to the continual debate within sociology about the role of sociological research in society and the applicability of the scientific method in research. An examination of specific examples of health care research illustrates both the spectrum of research as well the different theoretical and methodological approaches.

A. Research Methodologies in the Health and Social Sciences

Health and social service research draws on research methods from three areas of health care literature; community care, epidemiology, and health inequality and health behavior. Each of these areas has become associated with specific methodological traditions. An examination of three methodological approaches in health care literature serves to illustrate the strengths and weaknesses of different methodologies. Each of these research orientations and research methods offers an important input to the study of acute care. The community care literature, examining the

effectiveness of social policy utilises a tradition of small scale, in-depth qualitative research. Epidemiological research due to its emphasis on the changing nature and geographical distribution of disease utilises statistical analysis , drawing out the association between variables. Finally, the research on inequalities of health focuses on analysing national and local data on the social and economic characteristics in relation to health. Researchers conduct both small and large scale studies using a social survey technique.

A.1. Community Care studies: methodology;

The research in community care has established a tradition of examining the community care policy through the use of national and regional data, such as census data, and by conducting small scale in-depth interviews. Thus it generates a national picture of data trends against which the qualitative data can be juxtaposed. It was the rapid growth in the care of the elderly and the very elderly which initially raised the issue of who was to care for them. These concerns stimulated the development of a number of excellent small scale studies which sought to identify who cared for the priority groups, problems of need for both the individual and for their carers. Small scale, in depth interviewing has

proved to be a valuable tool because it offers the possibility for the interviewees to explain the meanings which they attach to their behavior, the opinions or beliefs they hold, and to provide the opportunity to recount events which have occurred. Small scale interviewing also provides data which is not collected by any large scale data base. They therefore have the potential to relate sociologically meaningful categories to one another, albeit on a smaller scale. Thus, for example, data can be collected on such things as 'who' is likely to receive social service help, the nature of the help which they receive, and the degree of need. Indeed, prior to these studies there was little or no idea of the large number of carers involved in caring for the elderly, the mentally ill and the disabled or of any of the problems they faced. Early examples of this work is that of Townsend and the work of Bayley in the field of mental health in the 1970's. [Townsend,P.,1979; Bayley,M., 1973]

Furthermore, qualitative observations on a small scale can also provide theoretical leads which at a later stage can become amenable to statistical analysis. This is often vital in an evaluation of health and social policy. Wicks's [Wicks,M., 1982] study, for example, of elderly people draws on census data to estimate the growing number of elderly in the future. In addition he uses interviews to draw out information on the degree of 'need', the receipt of services,

marital status and the availability of a main carer. Wick's study is useful for national social policy formulation and implementation. It provides an analysis of data and estimates of the relation between 'need', statutory provision and public expenditure.

Small scale research, furthermore, is effective in identifying sensitizing concepts and in the more detailed exploration of the meanings of ill health and disability for patients and their carers. Excellent examples of this small scale in depth research are Clare Ungerson's study of the carers of 19 elderly people and Enid Levin's study of the carers of the elderly [Ungerson, C., 1987; Levin, E., Sinclair, I. and Gorbach, P., 1983]. Clare Ungerson's in depth interviews of 19 carers demonstrated with great sensitivity the social and emotional rewards and difficulties of the relationships between the elderly person and their carer. It highlighted a number of aspects, such as the role of guilt, as well as the complex and subtle factors which governed these caring relationships. Ungerson's findings could not have been uncovered in a large scale social survey. These intangible but significant aspects to the caring function are not easily quantified or tabulated. From this detailed work Ungerson has been able to construct typologies which are useful for a broader number of studies and for health and social service policy. It is precisely these aspects of small scale research

which ethnographic research is so valued for. Enid Levin's study, also, provides an excellent example of the usefulness of this approach. Levin's study of elderly persons and their carers was conducted by in depth interviews. The interviews provided rich data which were used to identify particular categories of concern to carers. For example, she was able to identify four categories of problems for carers; social , behavioral, practical and psychological. The usefulness of small scale , qualitative work is therefore particularly fruitful for investigating a new field of research, generating new questions and for the formulation of general concepts, applicable to a broader range of cases.

A.2. Epidemiological studies: methodology

Epidemiological studies also draw on national data on morbidity and mortality in order to identify the distribution of ill health geographically. The strength of epidemiological data is that it identifies the distribution of ill health, along such indices such as class, age and sex. The studies typically focus on the relationship between a particular diagnosis and health outcomes, as well as the association between variables affecting the etiology of diseases. Epidemiological studies are quantitative in their approach.

The emphasis is on relating large numbers of individual indices to each other and treating the data with various statistical techniques. As a result, this type of research is particularly useful for identifying broad trends on a national, district or institutional basis.

The studies "Services for Stroke Patients one year after Stroke" [Legh-Smith et. al. 1986] and "Epidemiology and Health policy : Coronary Heart Disease" [Syme,S.L. ,1984] illustrate the methodological approach of epidemiological studies. The study on the epidemiology of coronary illness discusses the risk factors in the development of coronary problems and the implications for health policy. Similarly, a study by Dr. Hobkirk, illustrates the usefulness of epidemiological studies for the medical profession and the formulation of health and social service policy. Dr. Hobkirk conducted a follow up study of angina patients [Hobkirk,D.W., 1985] He followed up , 51 general practitioners in the Northern Region and identified 336 patients aged 30- 59 who had angina pectoris. Information was collected, using structured interviews, on their treatment and how angina affected their daily lives. Studies such as this one, are very useful for the medical profession because they both trace the use of services and need for patients and it also allows doctors to examine in a meaningful way different treatment strategies.

The focus of these studies is on the needs of a given diagnostic category and their after care in the community. Epidemiological studies provide a medical perspective which raises different questions which are pertinent to the development of health and social service policy. The strength of these studies is that they provide information on the utilisation of health services by particular categories of illness and 'need'. They are therefore important inputs into social policy formulation and implementation. The limitation of epidemiological studies is that they often do not give information on social class , related sociological variables or on the meanings patients attach to their responses.

A.3. Health Inequality studies: methodology

The literature on inequality and ill health traces inequality on national or regional scales, by measuring income , unemployment, car ownership, etc. Unlike the epidemiological studies , studies on inequality in health focus on social and economic factors which are associated with ill health. One of the most famous studies in recent years is the Black Report [Townsend,P. and Davidson,N. 1982]. The hallmark of the Black

Report is that it compiled data from a wide variety of sources and was able to demonstrate that inequalities in the distribution of health persisted despite the introduction of the welfare state. Thus it was able to use existing data and to compile it and to compare it in such a way to provide a coherent , logical and conclusive argument about the relationship between social class and health in England and Wales.

In more recent years there has been an increased interest in studies utilising large aggregated data provided by census data focusing on specific localities. These small area studies provide a wealth of data on housing, income, marital status, employment, and car ownership for specific geographic areas. The Health Divide: Inequalities in Health in the 1980s. [Whitehead, M., 1987] provides a marvellous resource by listing the numerous 'small area' studies. These studies use census data on wards to provide information on factors associated with ill health such as, overcrowding, car ownership, and unemployment to use as indicators of deprivation. Carstairs [Carstairs, V., 1981] for example, did a statistical study of 37 municipal wards in Glasgow and 23 in Edinburgh around 1971 census data, in which she found that greater mortality and morbidity were associated with areas of greater deprivation. Similarly, Thunhurst [Thunhurst, C., 1985] conducted a study of Sheffield 1981-1983 based on 1981 census material.

Thunhurst used eighteen indicators to define "Areas of Poverty" in Sheffield. He found a clear relationship between poverty and all causes of mortality for both men and women. The relationship was particularly strong for early mortalities and cancer in men. He employed both sophisticated statistical techniques and grass roots surveys to check and extend the statistical results. These studies have the advantage of pooling a large number of characteristics about different localities and compiling them in such a way which is useful for health and social welfare policy in these regions. Compiled these studies would provide a national input on health and social and economic characteristics of particular regions.

More recently there has been an increased interest in conducting in depth studies which explore the effect of income, housing, food and the 'culture of poverty' on health. Graham [Graham,H.,1986], for example, found that all household resources had the potential to influence health . The pattern of spending, however, varies between rich and poor people. The fixed costs of rent, fuel were paid first by the poor families, leaving food as a flexible expense. Fuel, housing and food represented 56% of the expenditure for poor families as compared to 36% for wealthier families. Graham [Graham,H. 1986] has also researched why some people practice behavior which is counter productive to health, such as

cigarette smoking. Graham points out that such actions , which would be labelled as irresponsible by the health professionals, is perceived by the mothers as a rational way of relieving tensions at the same time as fulfilling their responsibilities . These small, in depth studies, using semi structured interview techniques provide data about the meanings and rational which individuals use to explain, and interpret their everyday life events. There is also increasing interest to provide an 'actors' account, to document individuals perceptions of ill health, health control in relation to age and social class. Calnan's study provides an interesting example of how people explain social class attitudes and beliefs about health behavior, health control and vulnerability. This type of research provides the meanings for statistical data and is able to generate new concepts and theories, removing some of the limitations of national and regional data collection.

In summary, the review of the methodologies employed in health and social service research illustrates the variety of research methods. There is a close relationship between the types of 'problems', the research strategy and the nature and types of conclusions reached. Furthermore, the research 'problems' and methods highlight the tension within sociology between the positivistic and the humanistic schools of thought.

B. Philosophical Debates within Sociology

At the heart of the debate on research methodology is the ability of sociology to formulate problems and execute research which uses the scientific method. The tension centres on the two aspects of sociology ,the subjective 'meaningfulness' of social action and the social structure of society. These respective perspectives have influenced conceptions about the nature of sociological research, its methodology and its theories. They have been associated with different traditions in research methods , data collection and interpretation.

Juxtaposing the positivistic and the humanistic schools of thought clarifies the polarity of positions within the debate. The positivistic perspective is closely associated with the natural scientific approach which emphasises particular stages of development. It emphasises experimental research which is rigorous, repeatable, objective and falsifiable and produces laws or generalisations which are capable of explaining a broad range of facts. In contrast, the humanistic approach stresses the inter-subjective meaningfulness of social life. It points to the limited ability of the social sciences to conduct controlled experiments which have identifiable and

controllable variables, which can be repeated and verified. This perspective argues that the two prime distinguishing features which are fundamental to sociology are the dual problems of the 'self consciousness' and the fact that social systems are usually open, complex and varied. Indeed , many sociologists have argued, in the Weberian tradition, that empathetic understandings or *verstehen*, are of positive usefulness in conducting sociological research. These understandings generate hypotheses about human conduct which would otherwise not be possible. The very fact that social scientists are a part of society gives them a particular understanding of social processes. It is argued that as members of society they share with their units of research certain common understandings which generate sensitising concepts vital to conducting sociological research. Problems of concept formation differ in the positivist and humanistic research. On the one hand the positivist tradition is associated with quantitative data, associations between variables, definitive concepts [Bulmer, M., 1977], and theory testing. On the other hand, humanistic research emphasises the interpretative and inter-subjective nature of sociological research. It stresses qualitative data, sensitising concepts and theory generation.

The relationship between theory and research is another controversial issue among social scientists. The positivist

perspective holds that theories generate research strategy which in turn generates theory. The humanists however argue that methods are determined by perception of reality and linked to a theoretical standpoint. The positivist tradition conforms closely to the natural scientific method. It emphasises different types of questions from the humanist perspective. The positivistic perspective argues that qualitative research is subjective and not verifiable or falsifiable and therefore lacks justification. They argue that it is necessary to follow the traditional model of scientific research emphasising a logical sequence of steps which commences with reference to previous research, which in turn determines research design, research techniques and the interpretation of data. The humanists argue, in contrast, that raw data, or data treated with statistical analysis is not scientific and it does not explain very much about reality. The research techniques used to collect large scale data are unreliable because it is not known who answers the questions, how they interpret the questions or their degree of commitment in answering the questions. Therefore , what these large scale studies represent is abstracted from reality . It gives some limited information about indices but not about how social reality is construed.

II. Research Techniques

The analysis of the community care studies, epidemiological studies and the research on the inequalities in health, illustrate the fact that sociologists employ a variety of research techniques in order to obtain their data. Indeed, they often select two or more methods to complement one another. These research methods range from the utilisation of existing government data to large scale social surveys, using mail questionnaires, or the use of participant observation for small scale, geographically fixed, research. Each of these research techniques has strengths and weaknesses which need to be considered in the light of the particular research problem.

Social surveys are the sociologist's traditional method of data collection. The advantage of this type of research procedure is that a large or small number of respondents can be contacted, the questions and categories for analysis can be tailored to meet the needs of the individual researcher, as opposed to an outside institution. Furthermore, the questionnaire can be designed to the degree of detail required for the research. Social surveys can take a variety of forms. The main examples are the mail questionnaire, the structured interview and the unstructured interview. The structured interview avoids many of the problems associated with mail

questionnaires because respondents are interviewed individually and there is the possibility of establishing some rapport with the respondent. Establishing a relationship with the respondent usually results in a greater commitment to cooperation and better data. Structured interviews, in contrast to unstructured interviews, seek to standardise the interview as much as possible and to reduce the effect of the interviewer's personal approach. The unstructured interview, does however, have some strengths which are unique to it. Primarily the unstructured interview allows the respondent to emphasise those aspects of the subject which are central to how they understand, conceptualise and perceive a given 'problem'. The difficulties with this approach are numerous however. Firstly, long unstructured interviews are very time consuming and therefore it is often not possible to interview more than a few people. Secondly, due to the lack of a structured format it is possible for more interviewer bias to be created. Thirdly, the researcher may have interview notes which are not possible to relate to one another. In practice, a compromise solution is often employed in survey research. The semi structured interview bridges the structured and the unstructured interview by using some open ended questions with questions which have a set of fixed answers. This enables the researcher to obtain comparative data and to incorporate individual perspectives with the data interpretation.

The general criticisms of the social survey technique of gathering data reflect a concern with its non experimental design. A number of specific criticisms have been identified. The criticisms come from two different directions; the 'positivist school' and the humanistic critiques. The positivist school argues that social surveys fall short of experimental work because they do not clearly isolate or distinguish variables. They argue that observed differences between the experimental and the control group , or differences between variables in the social survey are difficult to distinguish from independent variables or extraneous circumstances. Another disadvantage often cited, is that the interview is located in a specific point in time and therefore has a restricted, temporal quality. Finally, another problem which positivists often cite, is the reliability of people's verbal accounts of what they think or believe. They argue that this is particularly problematic because individuals often have 'public and private accounts of behavior'.

The humanisitic school , in contrast, argues that the social survey does not really establish respondents meanings. The answers which respondents give often do not convey the meanings which are attached to them. However, the use of the semi-structured interview in particular, enables the accumulation of more in-depth data, which is sensitive to

individuals and individual meanings. It lends itself to small scale social survey research because it does require face to face interviews which gather both statistical and qualitative data. Furthermore, by using both a main questionnaire and a follow up questionnaire it is possible to establish better rapport, obtain more data and to avoid the problem of interviewing only at one specific point in time.

An important part of the social survey is a consideration of how the respondents are selected. The kind or type of respondents selected depends on the frame of reference of the inquiry. As it is not usually possible to conduct a social survey of every potential respondent, it is necessary to take a small sample of the desired population. A number of methods are used to obtain a representative sample. One device used is quota sampling. Quota sampling requires that certain specified characteristics of the respondents be present in the sample in the same proportion as they are in the general population. For example, the respondents must reflect the national distribution of diagnostic categories. It is useful for controlling for specific variables, such as age groupings, or sex diagnostic categories. The disadvantage of this type of sampling is that it is possible for the researcher unwittingly to introduce bias into his research in the selection of the sample. Another method of sampling is the random sample. Random sampling means that it is a method of selecting

respondents for study in such a way that each one has the same opportunity of being selected. This means, in practice ,that each respondent has an equal probability of being selected. Random sampling is often used in public opinion research, for example. The selection of quota or random sampling depend on the nature or location of the survey.

Thus a great deal of debate has focused on the contrasting research methods in sociology, Giddens [Giddens, A.,1976] however, argues that the methodological problems are not as acute as they have sometimes been argued. In New Rules of Sociological Method , Giddens argues , that there is a general level of understanding common to society and that there are no doubt single 'cultures', but individuals are capable of moving between them."The ordinary member of society quite routinely shifts between different orders of language and activity, as do scientists on the level of theoretical reflection" [Giddens,A., 1976, p. 18-19]. Following Giddens philosophical approach would suggest that sociological research between these two perspectives need not be as irreconcilable as has been traditionally thought. Indeed, Warwick [Warwick,D.P.,1983] argues that each research technique need not be used in singular form . In some research 'methodological marriages' are formed. The value of 'methodological marriages' is that one style of research may be balanced against the strengths of another style. A prime

example of this is that of Margaret Stacey's [Stacey,M.,1960] study of Banbury. In this well known community study intensive participant observation was used in conjunction with analysis of records, interviews and a sample survey. It is the diversity and multiplicity of methods available to the sociologist, and the variety of possible interrelationships between theory and method which reflect the complexity of the social world. Indeed what has been termed 'triangulation' emphasises the argument that the distinctions between different research methods need not be viewed as independent, self contained methods of social inquiry. In practice, different styles of research can actually complement each other.

III Research Methodology for the Study of Acute Care in the Community

It has been argued that policy problems , such as those arising in the organisation and delivery of health care, need to be approached both empirically and in terms of the 'problems of everyday life'. This is because health care problems are problems of national concern over public expenditure allocation and because they are problems of

practical urgency for individuals. The salience of health care research is clear in terms of individual lives and in terms of national and district health and social service policy. As Clare Ungerson so aptly wrote "policy is personal" [Ungerson,C., 1987]. Sociological research has the responsibility to indicate the extent to which our lives are affected by social and economic factors. Our lives are embedded in a socio-economic context and therefore to conduct research on an entirely subjective basis may lead to private constructions of reality which could obscure the tangible qualities of the world 'out there.' It is therefore necessary to construct 'methodological marriages' between different research strategies.

The problem of acute care reflects the fact that sociological research always is related to some fundamental problems both within sociology and within society. Research into the 'problem' of acute care is a particularly interesting because it raises both philosophical issues and practical issues in the formulation and implementation of social policy. The 'problem' of acute care raises issues about structure and agency. It is concerned with the government policy, with social and economic forces in society and it is concerned with the individual. Studies of acute care strike at the heart of epidemiological studies, studies of health inequality and community care. This is reflected in the changing conception

of the nature and origins of morbidity, the social class distribution of ill health and the shifting responsibility of care between hospitals and the family.

A. Defining the Field

What do we mean by acute care? The definition of acute care is not as straight forward as it might at first appear. This is a natural result of studying an area which interfaces a number of professions and the home. In this case it is of interest to hospitals, doctors, social workers , home help, and meals on wheels. Within the hospital community, and in the national data on morbidity certain illnesses are conceived of as 'acute illnesses' and this has been embodied in hospital wards and the national policy of community care. Thus patients who are regarded as disabled or elderly are distinguished from those who are 'acute' care patients. The hospital defines acute ill health in terms of patients who have suffered a sudden episode of acute ill health which requires medical or surgical intervention by a professional who has specialised in that type of illness. In contrast 'chronic' ill health and disability has come to be associated not only with reoccurring episodes of ill health but also with social services provision. A definitive distinction between the two is not possible. Blaxter [Blaxter,M. 1987] argues that the

meaning of disability has varied over time as well as according to the 'professional' defining institution [Blaxter,M., 1987, pp 2-7]. Hyman [Hyman,M.,1977] found that there was variability as to who was labelled as 'disabled'. In the study, The Extra Costs of the Disabled, it is argued that while costs varied with diagnosis, and is associated with a broad spectrum of ages, it does not adequately explain 'who' is disabled. The main criterion of disability appears to be the length of illness. In Hyman's study one quarter of the sample had been 'disabled for up to five years, while the others had been 'disabled' for longer periods. In addition the 'patients/clients' typically viewed the prognosis of their disability as static.

Attempts to measure health status and mobility have been made by formulating questionnaires which evaluate 'activities in daily living'. The National study, by Hunt [Hunt,A.,1978] of practical problems of the non - institutionalised elderly, focused on the capacity to complete daily activities, such as feeding oneself, bathing oneself, going out of doors, going up stairs, and cutting toe nails. Disability in practice, therefore becomes largely self identified and measured in terms of 'categories of self care' which include the ability to feed, wash, dress, and toilette etc. " The choice 'to become disabled' therefore depends not only on the severity of the symptoms but also on the perception of its

meaning " [Blaxter,M. 1987, p 13]. Disability is often labelled by the individual in order to obtain the help of social services for wheel chairs, allowances or other support. It does not therefore have any objective criterion . Many more people could be registered as disabled but choose not to for reasons of self image and inadequate information.

It can be argued that in practice the distinction between acute care and disability is actually often one of degree and length of duration. However the policy of community care emphasizes provision for the 'priority groups', the long term dependent. The prime criterion which acute care and the care for the chronically ill, the disabled and the elderly differ is primarily a question of time, the 'degree' and the persistence of the restriction of daily activities. In this study 'acute' ill health was defined by the discharge from surgical or medical wards from a district general hospital. [It did not include patients from geriatric wards]. It included patients of all ages who had been hospitalised for two or more days. The research raises the question of whether it is appropriate or to what degree it is appropriate to make distinctions of medical and social service support between the 'priority groups' and acute care patients.

B. Principal areas of investigation

The approach to the study of acute care in the community requires a research design which addresses the problem of acute care at two levels. It requires a 'methodological marriage' which spans the quantitative approach and incorporates the attributes of qualitative research, through the identification of meanings , perceptions and perspectives of individual actors . In order to combine these two approaches it is necessary to ground the research in one locality ;to gather national and local data and to conduct a survey of patients discharged from hospital.

In the first part of the research a quantitative approach is used to examine the national distribution of morbidity and this is compared to both the district statistics and MK hospital data. The rational behind this approach is due to the Milton Keynes Hospital's practice of discharging patients earlier and increasing throughput in the acute care wards. It is therefore necessary to examine the level of statutory medical support available in the community. The next step of analysis was to identify the major diagnostic categories for Britain and for the Milton Keynes Health District, in relation to the diagnostic categories of patients sampled. A comparison was made on the basis of age and social class as far as this was possible. The strong association between acute ill health

and deprivation suggests that some patients have greater need for statutory service support. A hypothesis is that there is a likelihood that those households which are most deprived are most likely to incur the most ill health and the after care for these individuals is also more problematic. This is even more likely to be the case among economically active age groups, the least well off and among the new population. The research seeks to identify the population 'at risk' and to thereby develop a more precise rationale for the allocation of general practitioners, community nurses and community occupational therapists for the after care of convalescing patients.

The second part of the research employed a small scale social survey approach. The semi-structured interviews were conducted with patients who had been discharged from acute general medical and surgical wards. The interviews seek to establish 'who' is to care for these patients after discharge what health and social service facilities are available , 'who' receives them, the nature of the care they receive, and the type and amount of patient 'need' in the community.

In addition, the research sought to evaluate 'what' type of care patients received in the hospital, in the family and in the community in general. It sought to distinguish between 'lay care' and professional care. The in depth interviews

sought to gain insight into the 'emotional content and loading' [Bulmer,M., 1986], from the patients perspective, of care in the community. In the home, the question of acute ill health or chronic ill health is primarily cast in terms of time, duration and the degree to which the illness has become absorbed or routinised in daily life. In addition, the degree of knowledge or familiarity of the illness influences the perception of ill health. Time influences both the degree to which the illness is routinised and the familiarity or knowledge the patient and their carer have of the illness. Since time or duration is a critical variable in distinguishing chronic or long term ill health from the acutely ill, it also raises the issue of the lack of familiarity or knowledge and the routinisation of daily life after an episode of ill health. It accentuates the 'career' of acute ill health and convalescence.

C. The Research Site

The research site for the study was one geographical area, the Milton Keynes Health district , a part of the Oxford Regional Health Authority. Milton Keynes is a particularly interesting area to study for a number of reasons. The foremost reason, is that the Milton Keynes District Hospital is at the forefront of National Health policy. It is

implementing the policy of increasing hospital throughput, increasing hospital efficiency and discharging patients more rapidly into the community. The average length of stay for general medical and surgical care is among the lowest in the country. A second reason, for the selection of Milton Keynes, is that it is a new hospital with a dynamic and energetic staff who support health care research. The third reason, for selecting Milton Keynes is that the rapidly expanding population of Milton Keynes is composed of a mixture of locally born and newcomers. The policy of community care particularly stresses the role of the statutory, voluntary services and the availability of friends and neighbors to provide support and assistance. These comparisons are more easily tested in a relatively new population. Finally, Milton Keynes falls within the Oxford Regional Health Authority, where the effects of the RAWP, are cutting back on the ORHA [DHSS,1981] funding despite the expanding population center of Milton Keynes within its boundaries. Furthermore Oxford RHA implemented its own policy of District self sufficiency and allocated resources accordingly. Milton Keynes , as a new District Hospital benefited from this. Thus the fact that Milton Keynes is a new district hospital, and the fact that it has a new and growing population with expanding health center practices make Milton Keynes a very unique area to study.

D National and Local Data Sources

Data was gathered from the Census, the General Household Survey, Regional Trends, the NHS Data Book, Hospital Inpatient data and from the Milton Keynes District Health Authority. Information was gathered on Regional expenditures, length of hospital stay, morbidity and mortality data. This data was examined to shed light on the implementation of the community care policy, the nature of the distribution of ill health and to compare the age, sex and class distribution of the sample.

IV The Social Survey

The second part of the research concentrated on a small sample of acute care patients discharged from the Milton Keynes District hospital. The purpose was to examine the differences between institutional care and community care , to evaluate the nature and type of care which they received in the community and finally to identify the degree and type of need experienced by convalescing patients.

A. Pilot Study

Initially a pilot study was conducted of 12 patients. The purpose of the pilot study was to implement and test the questionnaire, to become acquainted with the hospital routines and procedures and to analyse whether a broader or a narrower selection of patients should be interviewed. In addition, the pilot survey provided an indication of the total number of patients it would be possible to interview and the length of time it would take to complete an interview with a patient.

The pilot study was useful because it became obvious that while the instrument could be used in the manner it was set out it needed to be pursued at a leisurely pace to allow for the descriptions of the recent events. Patients and their carers typically enjoyed having the opportunity to discuss their concerns and in some instances to have a chat or to air any grievances. This substantiates the notion that interviewees are more likely to participate in interviews if they feel they gain from the interview. A few patients wanted to know that if the study did not directly benefit them that it would benefit other patients.

The pilot study was primarily composed of very elderly patients. This was not decided in advance , however it emerged

as a result of lack of familiarity with hospital routines and ward rounds and the hospital population. Interestingly, retrospectively, the pilot study, with its preponderance of elderly people had , a higher level of social service support in terms of home helps, and day care than the main study.

On the basis of the pilot it was decided to extend the study to include the economically active age group. The purpose of including the economically active group was to examine the kinds of needs and support of the younger patients in contrast to the 'elderly' who were being discharged. It was felt that it would be useful to explore ill health in relation to the two different stages of the life cycle. In this study there were two main categories of patients ; those who were in the economically active stage of the life cycle with teenage children still at home and retired patients and their spouses whose children had left home. It was postulated that the two different stages in the life cycle may have their own problems, differences in levels of family care, and different levels of statutory support. In addition it was estimated that the Milton Keynes hospital had a larger number of economically active patients than retired patients in its medical and surgical wards.

As a result of the pilot study it was also decided to conduct a follow up interview in addition to the main interview .The

main interview would take place one week after discharge , as it had been done in the pilot, and the second interview would take place at 6 weeks post discharge. The purpose of a follow up interview avoided the problem of interviewing at only one point in time, it would obtain better data , by establishing a better rapport with patients and it would allow for some evaluation of 'health outcomes'.

Overall it was decided to restrict the study to 45 patients. This would provide a manageable number of patients and their carers to conduct lengthy interviews with. With a relatively small number of patients it is also possible to become acquainted with each patient and their particular circumstances.

B. The Selection of Patients for the Study

In order to study patients discharged from hospital it was necessary to approach the Milton Keynes District Hospital to request access to patients. The Hospital Ethics Committee passed the proposal for the study of patients discharged from the hospital and their after care in the community in January 1986. The Committee also recommended that the Specialist in Community Medicine should be the hospital's internal supervisor for the research. General Medical and Surgical consultants were written to and invited to be involved in the

study. Five consultants from the general medical and surgical wards were extremely helpful. They offered access to their patients and were willing to discuss hospital routines and to provide general medical and surgical information. On the basis of discussions with the consultants, it was decided to approach 45 patients from general medical and surgical wards on the point of discharge from the hospital.

The patients interviewed consisted of forty-five patients discharged from general medical and surgical wards during a four month period from Milton Keynes District General Hospital. The patients were randomly selected from these two wards once certain criteria had been met. These criteria included the nature of the complaint, age and place of residence.

The patients selected consisted of patients who were in hospital for longer than two days in order to avoid trivial complaints. Also patients who were potentially unlikely to survive were excluded. These two criteria were pursued with the advice of the doctors. The intention was to restrict the study to patients with a modest variety of diagnoses whose medical condition would be likely to require some new medical skills or changes in life style as well as potentially some degree of need for medical or social services in the

community. Obviously the categories of trivial or 'unlikely to survive' were not clear cut, just as there is no clear cut distinction between 'acute' ill health and 'chronic' ill health. The distinction between these terms is often blurred by both clinical and self definitions.

The two wards selected were chosen to offer a variety of diagnoses, but not too broad in view of the small number of patients being selected. In addition the four wards only cared for adult patients and any patients 18 years and younger on those wards were not included.

A further restriction was made to ensure the consideration only of patients receiving Milton Keynes community services. Patients to be interviewed had to live within Milton Keynes and live in their own home and not in an institution .

Having stipulated these restrictions, the patients were selected randomly from the total population in the male and female general medical and surgical wards in the Milton Keynes District Hospital. The sample was selected to include almost equal numbers of males and females and to include a slightly larger number of economically active than retired patients. The number of patients to be selected for the sample was based on the rough observations of the inpatient population during the pilot study. The data from the Oxford Regional

Health Authority confirms a close approximation of the sample population to that of the total inpatient general medical and surgical population.

Table 8 demonstrates that the sample was quite representative of males and females in the total general medical and surgical ward intake. **Table 9** shows that the sample contained 10% larger proportion of retired patients compared to the total general medical and surgical wards during the four month sampling period .

Table 8. Male and Female Patients in Milton Keynes District Hospital in General Medical and Surgical Wards, [during March-June 1986] compared to sample.

<u>Hospital Inpatients</u>	<u>Total</u>	<u>%</u>	<u>Sample</u>	<u>%</u>
Males	1275	[54]	22	[49]
Females	1100	[46]	23	[51]
Total	2375	[100]	45	[100]

[Source: reworked data from Oxford Regional Health Authority Jan. - June 1986].

Table 9. Economically Active and Retired Patients in Milton Keynes District Hospital General Medical and Surgical Wards [during March June 1986] compared to sample.

<u>Hospital Inpatients</u>	<u>Total</u>	<u>%</u>	<u>Sample</u>	<u>%</u>
Economically Active	1577	[66]	25	[56]
Retired	798	[34]	20	[44]
Total	2375	[100]	45	[100]

[Source: reworked data from Oxford Regional Health Authority Jan. - June 1986]

The process of selecting patients was facilitated by ^{my} being permitted to attend weekly ward rounds with the consultants and junior doctors. The attendance at weekly wards rounds may have contributed to the success in gaining the co operation of patients. Patients were approached with a letter , explaining the purpose of the study and suggesting an interview a week after their discharge.

C. Main Survey

In total 49 patients were randomly contacted and agreed to

interview. One patient however died immediately upon discharge and another patient was living in a purpose built residence for the elderly and was therefore disqualified. There were only two patients who declined to participate in the study and there were no refusals at the time of the interview appointments. As Tables 8 and 9 indicate a total of 45 patients were interviewed. Twenty-five patients were in the economically active age group and twenty were in the retired age group. In the main survey a total of 22 males and 23 females were interviewed.

Although diagnostic categories were not specifically controlled for, diagnostic categories closely reflected the national and district morbidity profiles. Cardiovascular illnesses predominated in the study and this reflected the intake of the district hospital in the general medical and surgical wards.

Thus the sample, in general, provided a reasonable approximation of the hospital inpatients for these wards.

D. The Questionnaire

The questionnaire was designed to gather information which could both be tabulated , such as categories of illness, age,

sex, occupation and to elicit 'conversation' which would provide an account of the patient's or the carers experience of the illnesses and their after care. Therefore some questions were open ended and allowed patients or their carers to respond at some length. The first interview, at one week post discharge, was of approximately one and a half hours. The follow up interview, at six weeks post discharge, was a shorter interview, of one half hour to one hour in duration. It was designed primarily to gather information on the health status of the patient and to determine the level of statutory or voluntary support which the patient had received during the preceding six weeks.

The main questionnaire was divided into two parts. The first part was addressed to the patient and the second part was addressed to the main carer, if one was available . The largest part of the questionnaire was addressed to the patient. The first section of the questionnaire asked questions concerned with the patients reason for being in hospital and how long they had been in hospital. This was usually the topic which patients most wanted to discuss. The next section of questions were concerned with the social characteristics of the patients. Questions centered on who the patient lived with, the current difficulties they faced in daily living, such as mobility , pain and medications. Questions were asked of their 'life style habits ', their

educational attainment, occupation or most recent occupation, income and any financial difficulties. The second part of the questionnaire was concerned with questions of professional contact and sources of support from relatives and friends. Patients were asked whether they had been to the doctor or whether they had received any professional follow up in their home. These questions pertained to doctors, nurses, occupational therapists, social workers, home helps and meals on wheels. Patients were also asked what, if any, support they had received from volunteers, friends, relatives, neighbours. They were also asked if they had any needs which were not being met. Specifically they were questioned on particular practical resources, such as a telephone and a car, which would facilitate contact with other people or with the use of professional services. They were also asked questions which are often associated with 'deprivation' that is the condition of the home, whether it, for example suffered from condensation, lack of heating or over crowding.

The good co-operation and rapport with patients was evident by the fact that patients were appreciative of the interview. They particularly liked the fact that they had been approached in hospital first and therefore one had a closer acquaintance with 'their story'. In a few instances patients wanted to use the interview as a feedback mechanism either for commending the doctors and nurses at the hospital or for complaints.

Predominantly, however, patients found that the interview provided a 'follow up' from the hospital experience and a method whereby they could recount their experience to an 'outsider'. They welcomed the opportunity and the interest in their after care. The welcome, in itself, is significant and perhaps indicative of the frequently expressed abandonment which patients felt once they were discharged from hospital. Thus in terms of access to patients there were no difficulties encountered.

The more traditional problem of data reliability is often a difficulty with the nature of the questions being asked. The nature of many of the questions were predominantly 'factual' and not emotive in content. The magnitude and the recentness of the hospitalisation made it an event that most patients and their carers were eager to discuss. The nature and concern for the well being of the patients, which the questions suggested, would suggest that patients accounts were likely to be reliable. The reliability of questions which were more emotive such as the consumption of alcohol, cigarettes or fatty foods may be somewhat under reported. It is certainly well known in textbooks on questionnaire design and data collection [Bulmer, M. 1977 and 1982] that these types of questions are less likely to be reliably answered. The same may apply to questions of compliance with 'the doctors orders'. However, this is less likely as patients also frequently commented on

their respect and deference for the medical profession.

There were however variations in patients ability or willingness to answer the open-ended questions. In some instances interviewees simply did not appear to have thought what their current needs are and how they might be met from statutory or voluntary support. Another example is that patients and their carers had never considered the nature of hospital care vis a vis home care and therefore had little to say on the subject. Other patients, however, were very articulate and forthcoming and these interviews were rich sources of qualitative data.

The questions asked of the main carer sought to establish the relationship between the patient and social characteristics, such as, age , sex, health ,education, employment and care of any dependents. The carer was asked in what ways they helped the patient and the level of practical support they gave. Carers were also asked to give their estimation if the patient was still experiencing any medical or related symptoms , such as pain, sleeplessness, giddiness , tiredness or incontinence. Carers could often not put a direct estimate on the number of hours which they spent caring because so much of caring involved simply 'being available.' Carers were asked whether caring for the patient generated conflicts between responsibility for the patient and other responsibilities

which they might have, for example, a conflict between work and caring for a spouse.

E. Follow Up Questionnaire

The follow up questionnaire was designed primarily to focus on two sets of questions. First, it sought to identify the degree to which patients had improved during the intervening 5 weeks . Secondly, it sought to identify the level of statutory medical and social service support patients. It sought to identify if any groups of patients had not received medical or social support in relation to expressed need. Finally , the follow up questionnaire sought to identify the degree to which medical contact was initiated by the patients or by the medical profession.

The follow up questionnaire was extremely useful because the five week interval between interviews allowed for a passage of time which, in most instances, brought with it an improvement in patient health as well as time to organise whatever services or assistance they required.

F. Data Interpretation

The challenging and interesting data which emerges from this research exists at two complementary levels; the analysis of

aggregated data and the 45 in depth-interviews.

The statistical data was examined to identify characteristics of Milton Keynes and to establish trends in health care as well as to distinguish possible areas of 'risk' in the population.

The in-depth interviews sought to focus on the individual and to analyse if there were significant differences between social class, age, sex and length of residence of the patients and how this affected their after care in the community. The data was examined in the light of the experience of the patients' discharge from the hospital into the 'community' and the implications for the patient. The interviews revealed 'who' cared for the convalescing patient and the availability of statutory and voluntary support. The interviews were evaluated to identify differences between community care and institutional care as well as the nature of 'community' care from the patients perspective.

V Conclusion

Despite the controversies within sociology and its relationship to the scientific method it is beyond dispute that particular sociological problems have implications for the types of theory generated, research design and data collection. Whatever the sociologist's 'problem' it is of central importance to the question of how choices are made between

different research strategies. Each research problem leads to particular research designs and research methods tempered by what is practicable in terms of time and resources. Thus the logical model of procedures by which hypothesis are developed and tested , is not necessarily the same as the practice of research. In practice, there is a greater interaction between current research, observation and conceptualisation and research techniques are often combined to form 'methodological marriages'. Furthermore, the practice of research actually involves unexpected events, occasionally ethical concerns and the necessity to focus on particular dimensions of a problem to the exclusion of related but occasionally also relevant factors. Thus each piece of research uncovers an aspect of empirical reality.

The research on acute care in the community seeks to question current community policy, through an evaluation of national and local trends in morbidity, discharge policy and after care in the community. It's goal is to focus attention on the needs of convalescent patients in order to highlight the fact that today's acutely ill could become tomorrows prematurely elderly, long term disabled or handicapped.

Chapter 4

Oxford Regional and Milton Keynes District

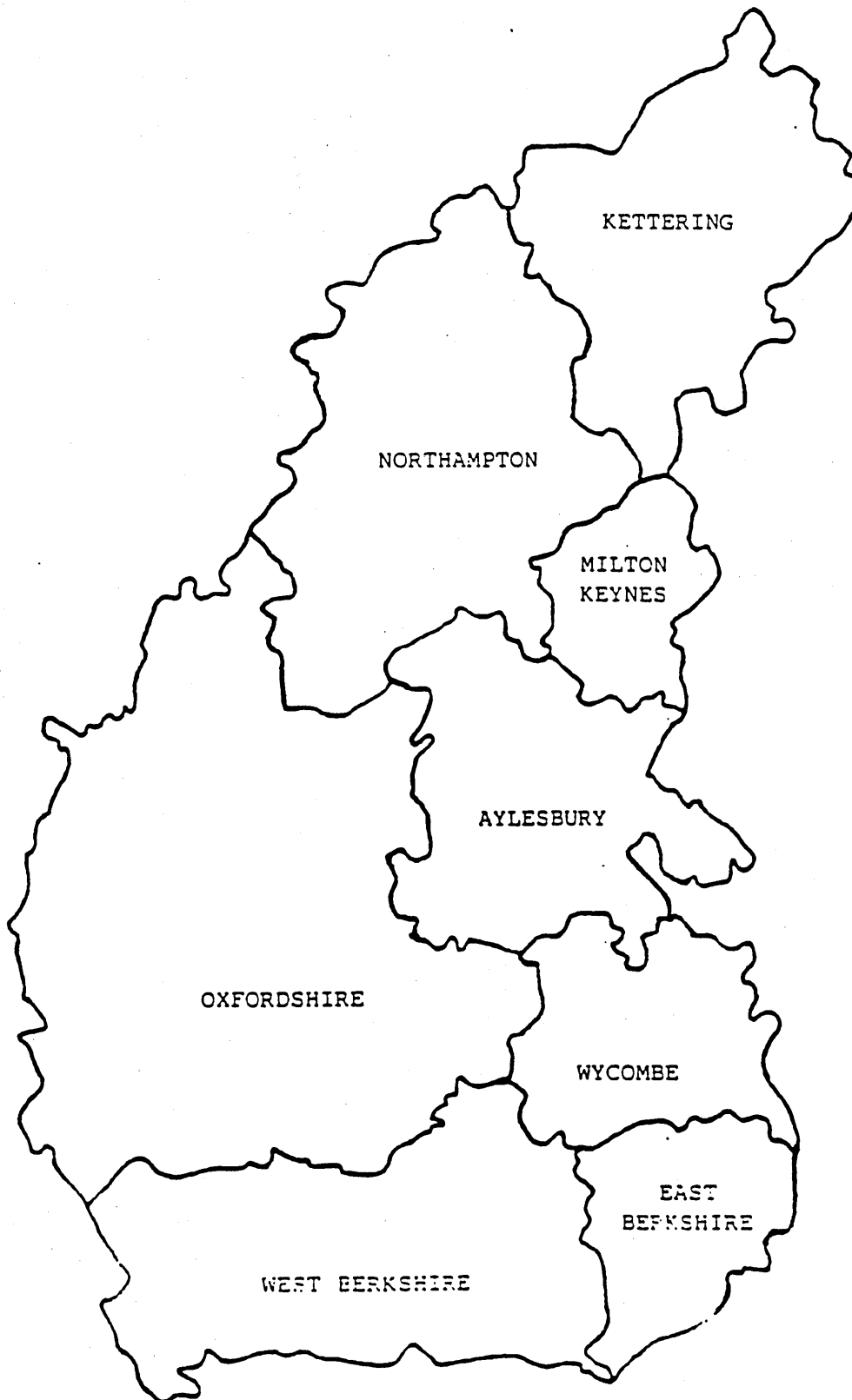
Health Care Policy

This chapter examines the objectives and implementation of the Oxford Regional Health Authority [ORHA] and the Milton Keynes District Health Authority [MKDHA]. Specifically, it outlines the ORHA and MKDHA plans as they pertain to hospital services and acute care . The policies are studied as they affect Milton Keynes. It is argued that as a result of the RAWP proposal of cutting Regional Health Authorities with the highest expenditures, the Oxford Region has now become one of the regions with the lowest expenditure and the most efficient resource use. The increased hospital throughput and earlier discharge policy pursued in Milton Keynes places it at the forefront of health service policy. This chapter questions how the criterion set by RAWP and the implementation of health and community care policy affect acute care patients. Specifically it questions whether current policy will meet current needs in Milton Keynes.

I. The Oxford Regional Health Authority

The Oxford Regional Health Authority [Figure 3] is at the forefront of implementing the national policy of care in the community. In 'Strategies for the Oxford Regional Health Care policy it states that it's objective is to 'reduce dependence on NHS facilities and depend on cooperation with other public, charitable and voluntary organisations.' It is based on a need to both avoid capital dependence and to be flexible with the fluctuation in available funds. Overall the ORHA is committed to a policy of being 'revenue oriented' [Oxford Regional Health Authority; Regional Strategy 1984-1994] and it therefore seeks to promote community care with less dependence on institutionally based services. In addition it has also established a policy of District Health Authority self-sufficiency. Along with tighter control over managerial and administrative efficiency the RHA intends to encourage self care through an emphasis on health education, encouraging voluntary groups and informal care by friends and relatives. The objective of greater 'community care' is reflected in ORHA acute hospitals policy. The plan proposes both a trend in shorter lengths of hospital stay and an increase of acute cases being treated as day surgery. It also seeks to promote independent living in the community for the elderly, the handicapped and the disabled with the support of community professional support.

Figure 3 Map of the Oxford Regional Health Authority



Consistent with the ORHA policy of reducing costs , the data presented in Chapter 1 [Table 1] demonstrates that Oxford RHA spends the least of any Regional Health Authority on per capita basis. For example, the Oxford RHA expenditure [1985] is £206 per head of population and can be compared to £232 for Yorkshire , £283 for Northeast Thames or £221 for the West Midlands. Table 1 also reveals that the ORHA has the second lowest total expenditure and it spends the least per capita.

Although the ORHA is at the forefront of reducing health expenditure a historical comparison of NHS, hospital versus community expenditure [Table 10] reveals that there has been an actual increase in hospital as opposed to community expenditure , in the last thirty years. The current percentage expenditure on community services stands at 6.4 per cent and expenditure on family practitioner services stands at 22 per cent.

In fact, the largest expenditure for community services was actually in the 1960's. In the three years since 1980, there has been a smaller proportion spent on community services and general practitioner expenditure as a percentage of total expenditure despite current discharge policies. This financial trend is a matter of concern in the light of the policy of discharging patients into the community earlier from acute

hospitals and long term institutions.

Table 10. Comparison of NHS gross expenditure-proportion spent on Hospital Services and Community Services, 1950 -1983.

Year	Hospital services	Community Health services	* General Practitioner	Other
	%	%	%	%
1950	54.9	7.8	33.3	8.2
1960	57.2	9.1	28.4	5.3
1970	65.2	7.1	25.3	2.4
1980	61.1	6.3	20.9	11.7
1983	61.9	6.4	22.5	8.9

*** General Practitioner services includes ; Pharmaceutical , General Medical, General Dental and General Ophthalmic.**

[Source: Compendium of Health Statistics, 5th edition, Table 2.6, 1985]

Table 11 demonstrates that the Oxford Regional Health Authority is at the forefront of implementing government policy. It has the second lowest hospital expenditure compared to other RHA's. In addition, as a percentage of it's budget it has the second highest expenditure on community services.

Table 11. Comparison of Hospital and Community Expenditure, by Regional Health Authority, 1982 - 1983.

RHA	Total	Hospital Services	%	Community Services	%	Family Prac- tioner	%
U.K	14,244.1	8358.0	58%	899.0	6.3%	3,168.7	22%
Northern	743.5	421.9	56%	45.8	6.0%	174.6	23%
Yorkshire	836.0	476.4	56%	51.5	6.1%	200.0	23%
Trent	999.7	568.6	56%	64.4	6.4%	237.1	23%
E. Anglia	427.7	234.1	54%	25.5	5.8%	106.0	24%
N.W.Thames	881.1	517.6	58%	56.9	6.3%	200.0	22%
N.E.Thames	1,059.8	669.3	63%	62.0	5.8%	203.0	19%
S.E.Thames	948.6	570.7	60%	61.5	6.4%	201.0	21%
S.W.Thames	728.2	430.3	59%	46.9	6.3%	163	22%
Wessex	614.7	340.2	55%	40.3	6.5%	154	25%
Oxford	489.9	266.5	54%	34.2	6.9%	126	25%
S.Western	740.1	411.2	55%	54.5	6.1%	188	25%
W.Midlands	1,146.5	657.5	57%	78.3	6.8%	277	24%
Mersey	607.4	359.5	59%	38.0	6.2%	134	22%
N.Western	1,040.8	584.2	56%	75.6	7.2%	228	21%

[Source: C.S.O. Regional Trends, 20, 1985 edition, Table 4.1]

Although the ORHA has the lowest per capita expenditure of all the Regional Health Authorities Table 11 shows that the ORHA

spends a smaller proportion on the hospital and a greater proportion on community services than other regions. Oxford Regional Health Authority hospital expenditure is slightly lower at 54% of total expenditure, compared to the regional average of 57% and Oxford RHA community services expenditure is among the highest, standing at 6.9 % compared to the average of 6.3%. Family practitioner services are also slightly above the regional average, at 25% rather than the regional average of 22%. Thus, while the ORHA is more supportive of community versus hospital expenditure than many other regions, it is a matter of some concern whether the low expenditure per capita is sufficient for fulfilling the objective of community care.

The low expenditure of the Oxford Regional Health Authority is reflected in the low community staffing levels. Between 1983 and 1985 the number of nurses remained static, the number of nurses in training dropped by 14% and the number of community nurses dropped by 7% between 1984/ 85 and this is a matter of concern. [ORHA Strategic Plan, 1986] The ORHA is also one of the most efficient in resource use. Data on length of hospital stay, availability of hospital beds and the use of available beds show that the Oxford RHA is one of the most efficient in the nation. It has the lowest average length of stay, the lowest number of available beds and the lowest number of occupied beds, compared to other RHA's. The average

length of stay of 7.5 days; which compares to the national average of 8.1 days. [NHS Hospital Administrative Statistics; Hospitals : Number of beds and patient activity in Regional Health Authority Areas, Table 4.7 in Health and Personal Social Service Statistics for England, 1985 ed. and Regional Trends, 20, 1985 edition, Table 4.4 and Table 4.5]. Table 4 provides a regional comparison of hospital throughput by providing data on the numbers of cases treated per available bed.

Table 12. NHS Hospitals, Cases Treated per Available Bed, 1983.

Region	All special.	Acute	Medical	Surgical	Obste- tric	Geri- atric	Psych- iatric
Northern	16.5	31.1	30.2	33.6	40.9	5.3	1.8
Yorkshire	17.5	31.9	28.1	35.5	43.4	7.3	1.9
Trent	17.8	35.1	32.9	38.8	43.7	6.6	1.8
E.Anglia	17.7	33.2	28.3	39.3	42.8	6.3	1.9
N.W.Thames	16.1	33.4	29.0	39.4	42.1	5.4	1.4
N.E.Thames	18.3	31.4	25.8	36.6	43.1	4.2	1.8
S.E.Thames	18.1	33.4	30.1	38.8	47.3	6.0	1.8
S.W.Thames	13.9	33.9	30.9	39.9	42.8	6.2	1.2
Wessex	18.2	34.7	31.7	40.6	45.6	4.5	2.3
Oxford	21.6	36.2	31.1	46.3	50.7	7.5	2.4
S.Western	16.4	33.0	33.9	38.6	48.9	5.8	1.8
W.Midlands	17.9	33.1	31.2	37.1	47.6	4.8	1.9
Mersey	15.8	31.7	28.5	34.9	45.4	5.5	1.6
N.Western	19.3	34.4	30.9	38.6	48.1	6.7	2.0

[Source: C.S.O.Regional Health Trends, 20, 1985 edition, Table 4.5]

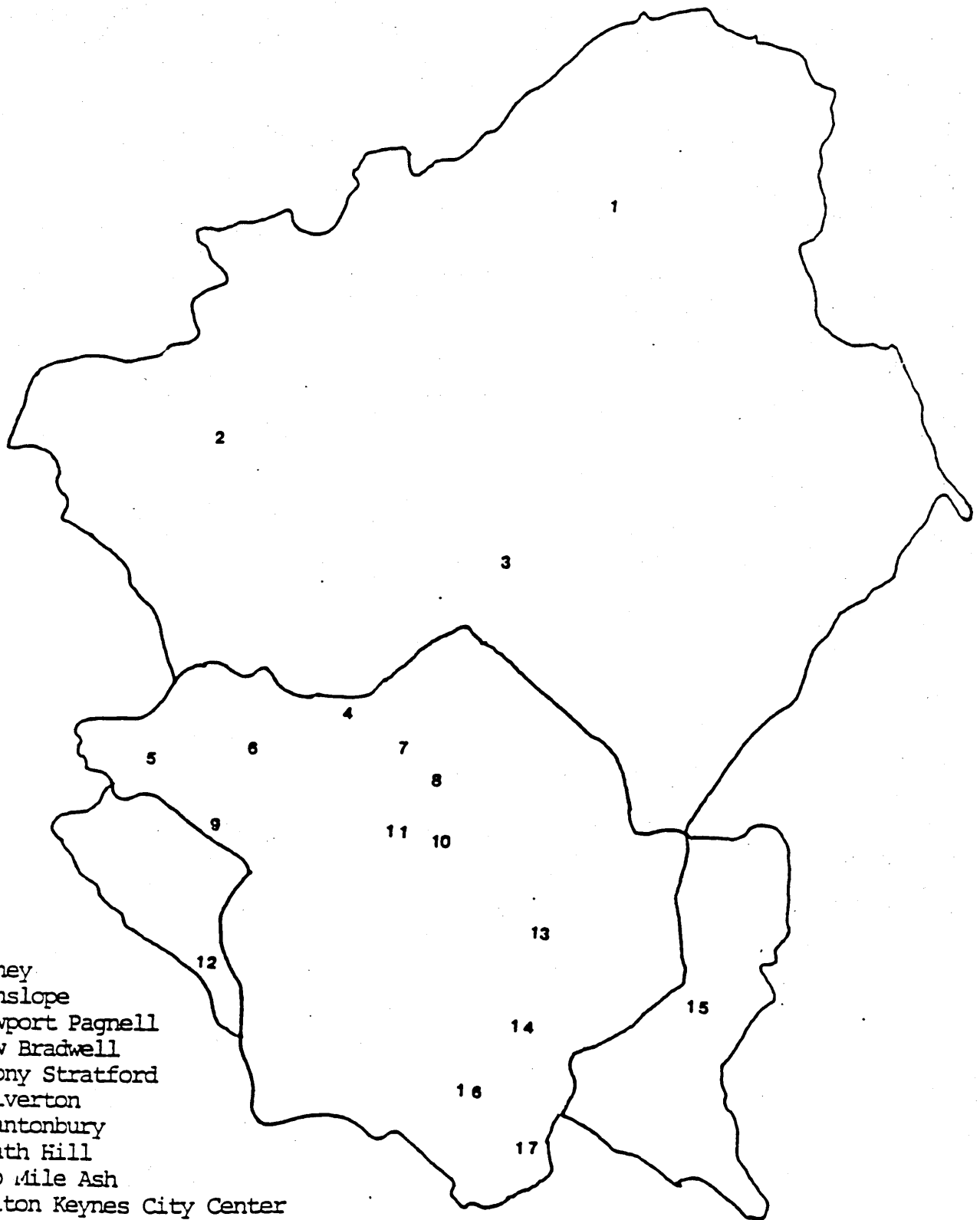
Table 12 demonstrates that the Oxford Regional Health Authority is at the forefront of making the maximum use of

each available bed. It has the highest throughput for surgical, medical, medical, obstetric, geriatric and psychological beds. It ranks first in surgical hospital throughput. Thus the ORHA is a leader in implementing government health care policy, both in terms of expenditure and resource use. However, this data must be interpreted in the light of the fact that real NHS expenditure has declined since the 1970's [Chapter 1]. Furthermore, the distribution of expenditure between the hospital and the community must be understood in the context of the region having the lowest per capita expenditure and that in the last thirty-three years of NHS expenditure , community expenditure is at one of its lowest ebbs.

II. The Milton Keynes District Health Authority

In devising the Strategic Plan the Oxford RHA expressed particular concern over the special needs of Milton Keynes, [Figure 4] the new city within its region. In particular, there was concern over the demands a new and expanding population in Milton Keynes would make on health services. The concern stemmed from the lack of social cohesiveness in a new population and from the demographic and social structure of the new city.

Figure 4 Map of the City of Milton Keynes



1. Olney
2. Hanslope
3. Newport Pagnell
4. New Bradwell
5. Stony Stratford
6. Wolverton
7. Stantonbury
8. Neath Hill
9. Two Mile Ash
10. Milton Keynes City Center
11. Bradwell Common
12. Furzton
13. Eaglestone
14. Netherfield
15. Woburn Sands
16. Bletchley

Specifically, the MKDHA expressed concern that the characteristics of Milton Keynes, such as a large new population, the socio-economic structure and a young family structure would place a high demand on professional community services.

A consideration of the objectives of the Milton Keynes District Health Authority and the characteristics of Milton Keynes provides an indication of the general demand on professional community services. In addition, Table 22 provides an over view of the composition of the 'community' to which patients are returned to post discharge.

The Strategic Plan for Milton Keynes defines as its' objective 'the provision of an efficient, cost effective service for the 16-64 year old age group, and for the 'priority groups'. The Strategic Plan's central concern is to provide a high standard of care for the population, both within the hospital and within the community. As part of its plan to minimize demands on acute and hospital services, the MKHA seeks to reduce length of stay, have a rapid throughput of patients, increase day surgery and to reduce long term institutional care. [Milton Keynes Health Authority, District Strategic Plan, April 1984] The MKDHA Strategic Plan also recommended, consistent with national and regional policy, that the

priority groups, should be cared for in the community with the support of health, education and housing services.

Milton Keynes District Health Authority revenue allocation stands at £ 19,618 K with £ 4,101 K budget set for Community and Mental Health Unit; Acute and Maternity budget allocation of £ 10,508 K and District Services and Headquarters budget set at £ 3,366 K. Table 13 reveals that the ORHA is one of the most efficient in the nation. Table 13 also shows that Milton Keynes surgical and medical wards are the most efficient in hospital throughput in the England and Wales.

The MKDH, in 1986, ranks first in surgery and fourth in general medicine compared to the other seven districts in the Oxford Region for patient throughput. In fact, the MKDH has a significantly higher throughput than the national average for all specialties except geriatric care.

Patient throughput per hospital bed is approximately 50% higher and the mean length of stay is 34% lower than the regional average.

The average length of hospital stay in Milton Keynes also shows it to be shorter than the national average in the general medical and surgical specialties. General medicine has an average length of stay of 7 days compared to the national average of 10.3 days.

Table 13. Milton Keynes Hospital Throughput, ORHA Ranking, Mean England and Wales, 1985.

1986	MKDHA [throughput]	ORHA ranking [1st = highest]	England & Wales mean
Gen. Medicine pts/bed	39.3 pts/bed	4th	33.5
Paediatrics pts/bed	85.5 pts/bed	1st	58.7
Geriatrics pts/bed	6.6 pts/bed	6th	7.2
Gen. Surg/Urol. pts/bed	52.2 pts/bed	1st	41.9
Ear, Nose, pts/bed Throat	67.1 pts/bed	4th	64.9
Orthopedics pts/bed	35.7 pts/bed	3rd	27.2
Gynaecology pts/bed	92.9 pts/bed	2nd	65.3

[Source: Health Means Milton Keynes, District Profile, Information Unit, Dept. of Community Medicine, June 1985]

Surgery has an even shorter lengths of stay, at 5 days per person on average, compared to a national average of 7.3 days [Source: MKHA, Information Unit, 1986].

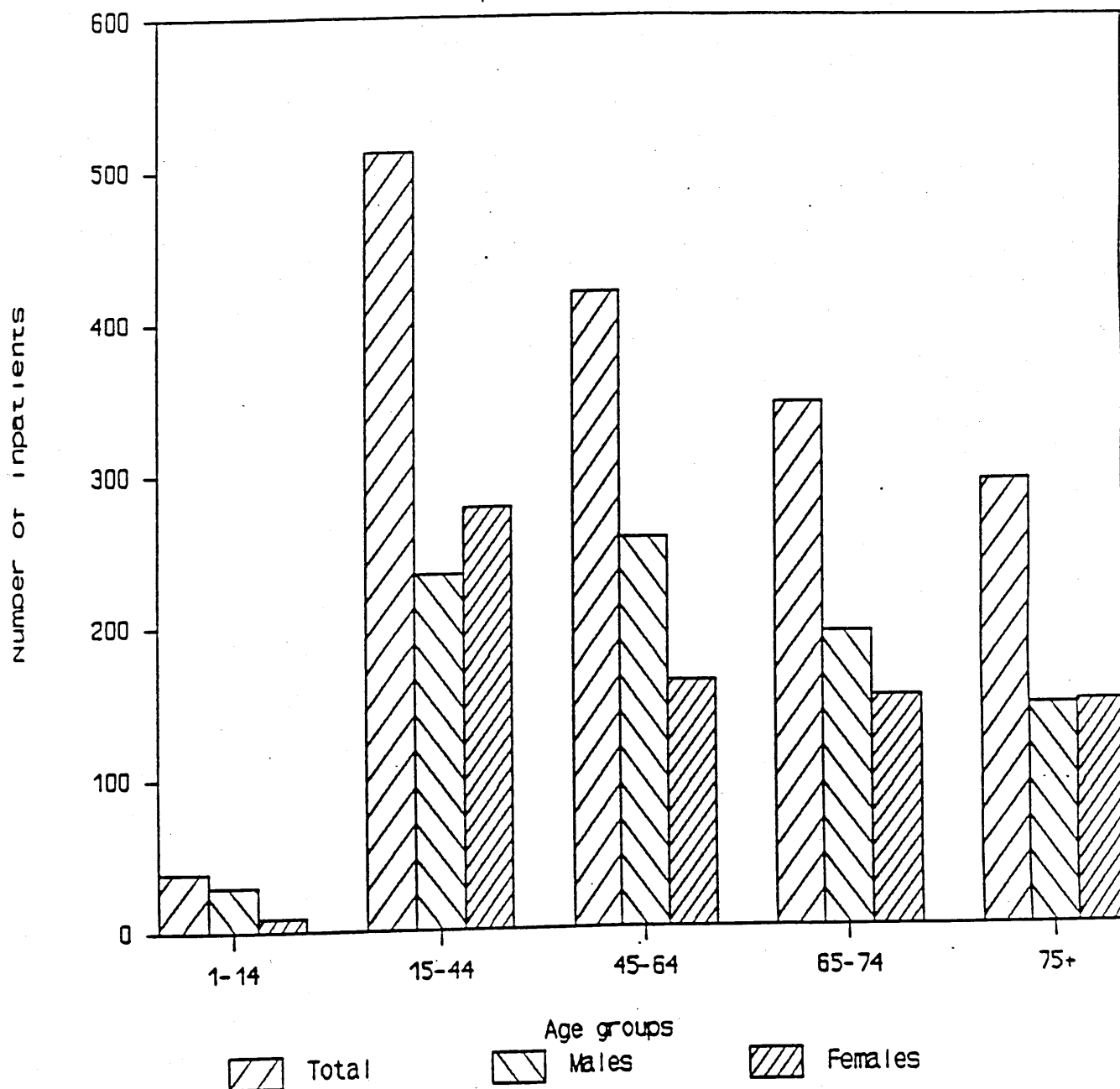
The short lengths of hospital stay and the rapid throughput of hospital patients place potentially very high demands and additional pressure on statutory professional community services. However, the growth in the number of community professionals, particularly community nurses, has been slow.

Figures 5 and 6 show the Milton Keynes hospital throughput by age and sex in the general medical and surgical wards. It gives the total numbers of patients discharged by age and sex per month and over the six month period. The General Medical Hospital activity for age and sex broadly reflects the national patterns of morbidity [OPCS, Hospital Inpatient data, 1984]. The economically active age group utilises the hospital beds more than the elderly. The economically active [15-64yrs. old] account for over 60% of all hospital beds in surgical and general medical wards and the elderly [64-75+ yrs. old] account for approximately 40% beds. In addition, males are represented in greater numbers in all age groups, except the over 75. Males account for 55% of all economically active and retired patient beds and women account for 45% . This is indicative of the greater longevity of women. It also however suggests that women are more likely to be fulfilling a convalescent caring function in the home.

**Figure 5. Milton Keynes District Hospital Activity:
General Medical Wards ,Inpatients by Age and Sex, January to
June, 1986.**

General Medical Wards

Inpatients Jan-Jun 1986

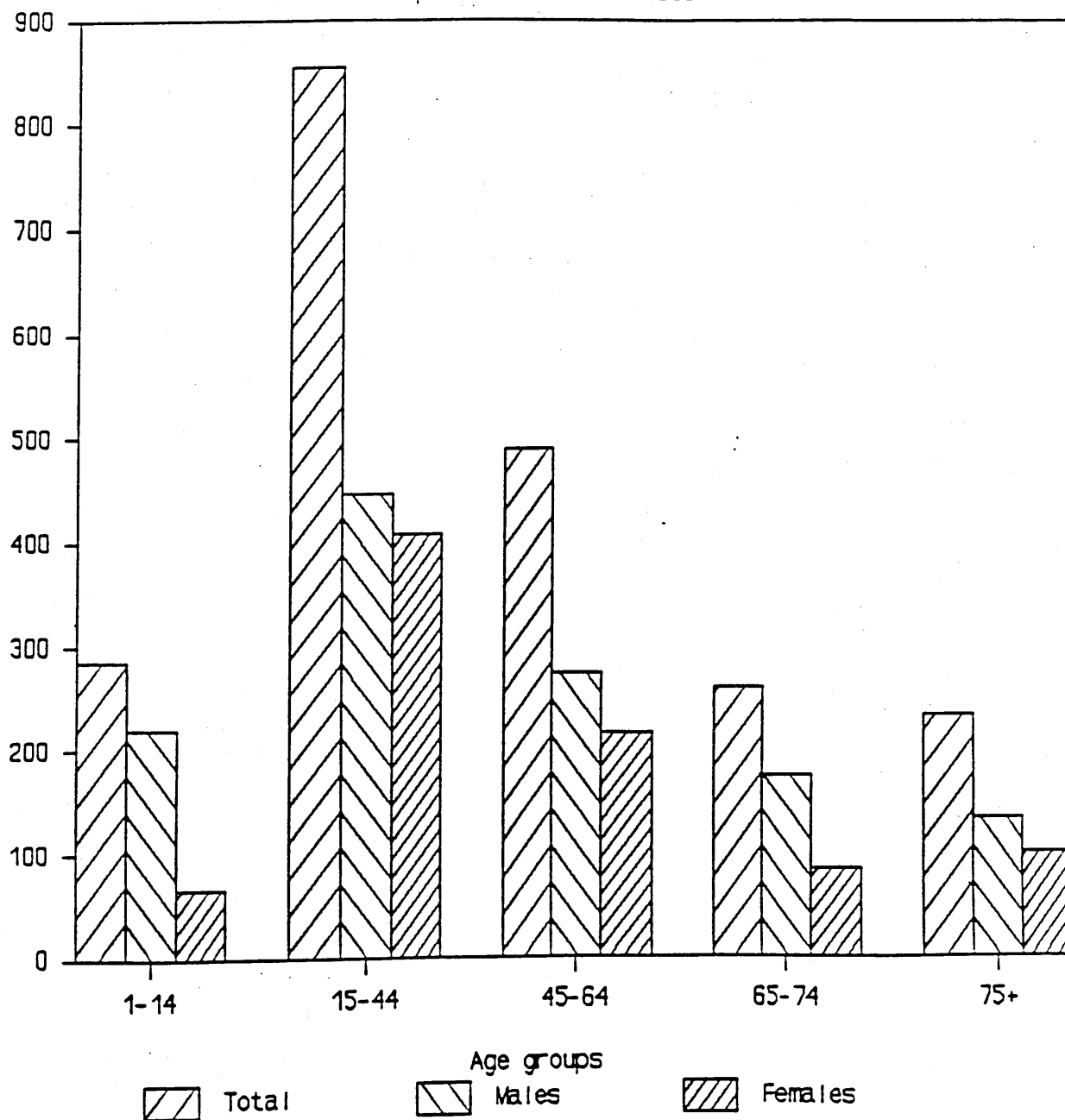


[Source: Oxford Regional Health Authority, computer printout]

**Figure 6. Milton Keynes District Hospital Activity
Surgical Wards, Inpatients by Age and Sex, January to June
1986.**

Surgical Wards

Inpatients Jan-Jun 1986



[Source : Oxford Regional Health Authority, computer printout, 1986]

In terms of the total number of patients seen surgery has a higher throughput than general medicine. This is reflected in the higher discharge rates and shorter lengths of stay [Table 13]. Figures 5 and 6 show that surgery patients are younger than general medical patients, with the largest number of patients in the 15 - 44 year old age group, and the 45 - 64 year age group constitute the second largest age group. The economically active age group [15-64 yrs] accounts for 71% of surgical patients and 58% of general medical patients. In contrast, the elderly account for only 29% of surgical patients and 32% of general medical patients. In terms of the absolute numbers of patients the data shows that there were 2,185 patients in the economically active age group, in this six month period, compared to 1,183 elderly. This data also clearly shows that surgical patients are substantially younger than general medical patients. The data also shows that men experience more hospitalisation than women.

In general medical and surgical specialties alone there is an average monthly discharge of 561 patients. Furthermore, over the six month period , January to June, 3,368 patients were discharged from general medical and surgical wards. This has considerable implications for after care of patients in the community, for the family, for health centers and community nursing and social services. The numbers of general practitioners, and nursing staff in the community must be

understood in relation to the average length of stay, and the hospital throughput.

A. Family Practitioner Services:

Primary health care, in Milton Keynes, is provided by general practitioners and through community health services . The community health services include health visitors , district nurses, midwives and psychiatric nurses. The responsibility and role of the primary health care team has had increased pressure as a result of the trend towards earlier discharge of patients after acute hospital treatment .

General Practitioners are established in health centers in different locations in Milton Keynes. They share a responsibility with the DHA for community services . In 1986, Milton Keynes has a total of 27 G.P. practices , [and one part time one in Furzton] with a total of 91 general practitioners. These G.P. practices are distributed in the new city and in the rural outlying areas, they encompass ; Bletchley, Central Milton Keynes , Eaglestone, Hanslope, Neath Hill, Netherfield, New Bradwell, Newport Pagnell, Olney , Stantonbury, Stony Stratford, Two Mile Ash, Woburn Sands and Wolverton [Figure 4]. The average list size of the general practitioners

in Milton Keynes is 1,580 patients,[MKDHA, April 1984], although there is some variation between the health center areas. A rough calculation of the distribution of health centers and the number of general practitioners indicates variations within Milton Keynes. In 1986, East Milton Keynes has 30 general practitioners, South Milton Keynes has 34 general practitioners and North Milton Keynes has 27 general practitioners. Using population estimates for wards in Milton Keynes it is possible to make rough, but not conclusive, estimates of the population for each health center catchment area. The calculations suggest that there are considerable variations within each health center catchment area. Estimated general practitioner list sizes for Eaglestone, Wolverton, Netherfield and Newport Pagnell are particularly high. All the areas in Milton Keynes are experiencing population growth, [Health Centers in Milton Keynes, a report by the Milton Keynes Community Health Council, Jan. 1985]. The variations of list size are of some concern due to the socio-economic structure of Milton Keynes city, [Table 18] and the rapid throughput and rapid discharge.

B. Community Nursing Services:

Community nursing services are organised with the DHA and with G.P. health center practices. In recent years the Local Authority has been withdrawing support of community nurses attached to G.P. practices and this has resulted in G.P.'s having to fund additional nurses. The responsibility of community nurses is to support the local general practitioners and practice primary health care. Patients are referred to them by the general practitioners and through the Community Nursing Liaison officer at the hospital.

The MKHA has, however, indicated its intention to develop appropriate community services to support those who leave hospitals and similar institutions. In order to implement this philosophy the District has as its objective 'to ensure growth in community staffing levels wherever population growth and workload merit.' Secondly, it has as its objective to facilitate the development of good liaison between General Practitioners, Social Services, Community Health Services and Volunteer Organisations in the interest of primary health care teams. The number of nurses and health visitors varies with each health center. Current levels of Community Nursing Staff are given in Table 14, with a breakdown of their geographical distribution.

Table 14. Health Center, Health Visitor and Nursing Services, 1986

Health Center Location	Health Visitors		Nurses		
	F/T	P/T	F/T	P/T	AUX.
NORTH MILTON KEYNES					
Stantonbury	4		3		1
Wolverton	4		3	1	1
CMK	3		1	1	
Stony Stratford	3		5	2	1
Total	14		12	4	3
EAST MILTON KEYNES					
Eaglestone	5	1	4	1	1
Newport Pagnell	1	2	3	2	1
Neath Hill	3		2	1	1
Woburn Sands	2		1		
Total	11	3	11	4	4
SOUTH MILTON KEYNES					
Bletchley [Water Eaton]		4	3	1	1
Bletchley [Whalley Drive]	3	2	4	1	
Bletchley [Bedford Street]	1	1	3	2	
Two Mile Ash	1	1	1		1
Total	9	4	11	4	2
TOTAL	34	7	34	12	9

[Source: Milton Keynes Health Authority-Community Nursing Staff List, March 1987]

Table 14 reveals that there is some variation in the numbers of nurses available in the different areas in Milton Keynes. The southern part of Milton Keynes is the worst off, with fewest health visitors and nurses. The northern part of Milton Keynes, particularly the Stony Stratford Health Center, is better off, both with a smaller population and a larger number of community nurses.

C. Social Services:

The Buckinghamshire County Council is committed to implementing the community care policy. It is committed to providing as normal a life style as possible for people with severe disabilities, the mentally ill and the elderly. The goal is to seek alternatives to residential care and to develop methods of preventing permanent residential care. The funding for the Social services is from the Local Authority rather than the Health Authority. However, the Health Authority has recommended that there should be some joint funding with the local authority in order to develop care in the community. However, current community care policy ignores the needs of those who do not fall into the 'priority' categories.

In Milton Keynes there is a policy to decrease the number of

elderly in long stay residential Local Authority homes . However, there has been a growth in the number of places for the elderly in private residential homes. It has been estimated that Milton Keynes has 45% more private nursing homes than the regional average. A consideration of the Costs of Social Services indicates recent trends in policy implementation. The cost of the care of the elderly has decreased, and there has been a decline in the number of residents in Local Authority residential homes. In one year there was a one per cent decrease of residential placement and a 10% increase in the number of contact hours of home help services. This suggests a decline in the numbers of people in Local Authority residential care and an increase in the use of private care as well as a modest growth of the elderly remaining in the 'community'.

The Social Services report indicates a modest growth in community care services [Table 15.] However, the policy is committed to positive discrimination of statutory services in favour of the elderly. As Blaxter argues, in "The Meaning of Disability" ", agencies can only conceive of a world of clients in terms of the universe they know" [Blaxter, M. 1987 p.7]. Table 15 reveals current social service policy is oriented towards the care of the elderly and does not make specific provisions for younger age groups.

Table 15. Social Services Report and Accounts 1984-1985,
Buckinghamshire County Council, 1986.

Comparative Costs and Statistics

	Bucks	1983 - 1984 6 Counties	39 Counties	1985 Bucks.
Care of Elderly supported residents 65+ in residential homes as % of pop. aged 75+	3.16	3.02	3.15	2.67
Gross cost per week in L.A. home, excluding capital charges	£ 106.37	100.89	93.37	118.51
Home Helps- contact hours per 1,000 pop. 65+	9,149	9,335	9,731	10,449
Social Workers per 1,000 pop.	0.35	0.40	0.42	0.42

Source: Buckinghamshire County Council, Report and Accounts , 1984
[1985]

Notes:

6 counties refers to Buckinghamshire and neighboring counties of
Bedfordshire, Berkshire, Hertfordshire, Northamptonshire and
Oxfordshire ; 39 counties refers to the average of all English
shire counties including Buckinghamshire }

County population figures on which the figures are based are the
Council's estimates of 592,800 in respect of 1983-84 and 599,400
in respect of 1984-85.]

III. The Social and Demographic Characteristics of Milton Keynes

Age and social class are two major determinants of health care usage. The RAWP report based its recommendations on age and standard mortality ratios. Later work [Thunhurst, C. 1985,; Jarman, B., 1983] has had as its objective a weighting of social class as an indicator of health deprivation and need. Jarman, specifically identified ten characteristics which were significant factors affecting general practitioners work load [Jarman, B. 1983; Milton Keynes District Information Unit, 1986]. Jarman's indicators include factors which, in recent years have been associated with general practitioner workload. For example, there has been interest in the demands that a new population, with few local social bonds, place on use of health center professionals [Miles, D.P., 1983]. Indeed the Milton Keynes District Profile indicates high use of the hospital services, even allowing for case mix and age. There is concern about the availability of friends and neighbors to care for those discharged into the community in the context of a community care policy implemented in a new city [Bulmer, M. 1987; MKHA, District Strategic Plan, 1984-1994].

Jarman's innovative work identifying Underprivileged Areas [Jarman, B. BMJ., 1983, and 1984] established criterion, as indicators of high demand on general practitioners workload. The indicators suggested by Jarman were; the numbers of the

er 65, those living alone; the number of children under the age of 5; the numbers of unskilled workers and the number of unemployed; the quality of the housing; in terms of the amenities and crowding; migration, people who have moved in the last year and minority ethnic groups; specifically those from the New Commonwealth and Pakistan as a percentage of all residents in private households. Thus, the structural factors which are significant in influencing vulnerability to ill health are associated with age, employment, quality of housing, income and social support.

The significance of the Jarman 'Underprivileged Scoring' in relation to the community care policy revolves around the concept of 'need' in the population. It is aimed at identifying areas of relative deprivation using a scoring system on which to base relative comparisons. This provides an estimate of both 'who' is likely to incur ill health but also 'who' is available to provide convalescent care. It points to the relative material and social context in which the care will be provided.

The Information Unit at the MKDH applied the work of Jarman to the District Health Authorities within the ORHA and within Milton Keynes [Table 16].

Table 16. Jarman's Indicators Applied to Oxford District Health Authorities: Social Demographic Comparison, Information Unit, Dept. of Community Medicine, June 1987]

Elderly 65 Alone	Children 0-4	1 par	Economic Unsk Unem	Housing Amen	Migration Crowd	Add	Eth	SCORE J 10	OXFORD RHA
11 4	7	2	3 6	3	8	10	8	-19	E.Berks.
12 4	6	2	3 5	2	6	11	4	-23	W.Berks.
11 4	7	2	3 5	2	5	12	4	-21	Ayles V.
12 4	6	2	2 5	2	5	9	5	-34	Wycombe
9 3	9	3	4 9	1	6	14	4	- 4	M.Keynes
14 5	7	2	5 12	3	6	9	3	2	Kettering
13 5	7	2	4 7	2	5	10	3	-10	Northamp.
13 4	7	2	4 7	2	5	12	3	-14	Oxfords.

[Source: MKDHA ,Health Means Milton Keynes, Information Unit, Dept. of Community Medicine, June 1987]

Key

65 = Over 65
 Alone = Pensioner alone
 0-4 = Under 5 years
 1 Par = One parent
 Unsk = Unskilled
 Unem = unemployed
 Amen = Amenities
 Crowd = Overcrowded
 Add = Changed Address
 Eth = Ethnic Minority

On the basis of this work it was calculated that Milton Keynes vis a vis other areas of the Oxford Region was most affected by the number of newcomers, the number of unemployed and finally, the fact that Milton Keynes has relatively more children compared to other areas. The two variables which were least significant in the case of Milton Keynes were the 'numbers over the age of 65 ' and 'housing lacking amenities'.

The relative lack of significance of those age over 65, is due to the fact that the current demographic structure includes comparatively few elderly in Milton Keynes. Furthermore, Milton Keynes scores very well on 'housing amenities' due to the large amount of new housing construction in the last ten years. The use of 'housing tenure' as an indicator of housing quality is somewhat misleading as some of the property in worst condition is owner occupied, although in Milton Keynes it forms a small percentage of the total housing stock.

The interpretation of the scoring method in Table 16 is based on the fact that for each of the scores the average is zero and a minus sign means a score below average, in other words a 'better' score. Table 16 demonstrates the large impact that a new population has on the score of Milton Keynes, scoring 14 as opposed to an average of 10 for DHA's, thereby significantly raising the underprivileged area score. The results show that using the 8 indicators; children: 0-4 & 1 parent; economic: unskilled & unemployed; migration: changed address & ethnic minority, Milton Keynes scored the 44th worst out of a total of 405 local authority areas. Within Milton Keynes, using Jarman's 8 indicators it was found that Bletchley [Water Eaton] was the most deprived area in Milton Keynes, precisely, in the southern part of the region where there are fewest professional services.

A close examination of the social and demographic characteristics of Milton Keynes highlights those aspects of the structure of Milton Keynes which the work of the Milton Keynes Information Unit found to be particularly significant in scoring Milton Keynes as an 'Underprivileged Area'.

A. The Population and Age Structure:

The Milton Keynes population is one of the most rapidly expanding in Great Britain, with an 107.6% increase in the ten years between 1971 and 1981 [MKDC 1981 Census Report] The majority of the households in Milton Keynes have been resident 10 years and less. Seventy-two percent of all households in Milton Keynes have moved to Milton Keynes in the sixteen years between 1967 and 1983. Between the years 1968 and 1973, 49% of the households moving to Milton Keynes came from London, attracted by the greater provision of rental housing. In more recent years households have moved to Milton Keynes from the surrounding areas and have bought property in Milton Keynes.

The demographic structure, like many new cities is relatively young, with higher numbers of people in the pre-retirement age groups than the rest of England and Wales. This is important in calculating the number of general acute beds needed, as 60% of all acute beds are occupied by the under 65's. The percentage of elderly living in Milton Keynes is below the

national level. Although, the Milton Keynes Household Survey shows a 26% increase in the number of 60/65 - 74 year olds between 1981 and 1983 [MK. Household Survey, 1983].

The Milton Keynes Household Survey provides data on the age distribution of the population within Milton Keynes [Table 17]. It reveals not only the regional variations in the distribution of the population but also shows the variation of the age structure within a district health authority.

The New Town Grid shows the highest number of people in the child bearing and child rearing stage of the life cycle. The existing villages have been affected by the New Town development and contain a younger population than might otherwise have been expected. Table 17 furthermore reveals that Stony Stratford and Wolverton have the greater proportion aged 60 years and older; with 19% compared with 15% in the villages, 12% in Bletchley and only 10% in the New Town Grid. These population distributions affect both the overall demand on health services but also the local demands on specific health center areas.

Table 17. Geographical Distribution of Age Groups in Milton Keynes, 1983. [between established and new city housing]

	Bletchley	Stony Stratford & Wolverton	Villages	New Town	Total City
Ages < 20	37.9	32.9	31.5	35.3	35.6
Ages 20 -44	37.4	35.4	42.3	45.8	41.6
Ages 45 -60	13.0	12.3	11.1	8.6	10.8
Ages 60 -75+	11.7	19.3	15.1	10.2	12.0
Total	100.	100.0	100.0	100.0	100.0

[Source : reworked from MKDC, Milton Keynes Household Survey, Demographic Report, 1983]

B. Social Class Structure in Milton Keynes

Social class is often used as an indicator of rates of morbidity and mortality and as an indicator of G.P consultations. The Black Report for example shows a class gradient for mortality, morbidity [as calculated by absence from work] and rates of long standing and acute illness and consultations [Townsend,P and Davidson,N., 1982, pp 68-73]

The data indicates increased mortality and morbidity with declining social class in all age groups.

In Milton Keynes there is a larger percentage of heads of household in the lower social groups compared to both the Oxford Regional Health Authority and compared to England as

a whole. Table 18 provides comparative data for the Milton Keynes District, the Oxford Regional Health Authority and for England and Wales.

Table 18. Social Class of Heads of Household in Milton Keynes, ORHA and England and Wales { % in each Social Class 1981 }

Social Class	Percentage of Households		
	Milton Keynes	ORHA	England & Wales
I Professional	4.9	5.0	3.9
II Intermediate	18.4	21.4	16.9
III [N] Skilled - Non-manual	10.0	9.2	9.2
III [M] Skilled - Manual	27.0	21.4	21.2
IV Partly Skilled	11.3	10.1	10.6
V Unskilled	3.1	2.7	3.4
Armed Forces	2.3	2.3	2.0
Inactive Heads	22.9	27.0	32.8

[Source: Health Means Milton Keynes, District Profile, Information Unit, Dept. of Community Medicine, June 1987]

While Milton Keynes has a higher percentage of people in Social Class I and II, and a lower percentage of inactive heads of household, it does have a larger percentage of people in Social Class III and IV than England and Wales. Social class III and IV account for 38% of the total population as opposed to 31% for ORHA and for England and Wales.

The larger percentage of people in Social Class III and IV socio-economic categories would suggest that Milton Keynes would have higher morbidity rates than the ORHA and the

national average. It would suggest that greater demands would therefore be placed on the hospital and community services. This is reflected in the hospital activity, which has a high proportion of economically active patients in surgery and in general medicine .

The unemployment rate in Milton Keynes is currently 11.4%. The unemployment rate is therefore below the national average of 13.6% . However, the geographical distribution of unemployment within the city indicates a concentration of unemployment in certain areas of Milton Keynes. The highest concentrations of the unemployed are in the wards of Linford, Fenny Stratford, Pineham, Eaton, Bradwell and Woughton. However, the unemployment rate , as a percentage of the total economically active population, is highest in Fenny Stratford, Woughton, Eaton and Pineham. The long term unemployed, is often used as an indicator of an area of deprivation. The Eaton ward has 45% of it's unemployed population as long term unemployed, Fenny Stratford has 37%, Pineham 34% and Stantonbury 37%, Stony Stratford 34% and Woughton 39%. [Source: Urban Studies Center, Milton Keynes, 1986]

In spite of the fact that Milton Keynes has a relatively young population, the data on hospital activity in General Medical and Surgical wards shows that 1577 economically active and 798 retired patients were discharged in the four month study

period. The large throughput of economically active patients reflects the young population structure of Milton Keynes.

Overall, the social and economic structure of Milton Keynes can be contrasted both within the new city and the rest of the ORHA. The demographic structure of the older towns of the new city; Stony Stratford ,Wolverton, Bletchley and Newport Pagnell have the greatest proportion of elderly residents and also the greatest number of 'locals', that is, people who have grown up and lived in the area all their lives. In contrast, the oldest new city housing, is approximately 15 years old and has a comparatively new and young population structure. The new city housing is predominantly occupied by couples in the child rearing stage of the life cycle; the 25 to 45 year old age group. In recent years, however, purpose built housing and sheltered housing schemes have attracted a greater number of elderly people. The new city housing has also attracted single people and a significant number of single parents. The areas of highest population growth between 1981 and 1986 have been Fishermead, Giffard Park, Great Holm, Two Mile Ash and Heelands. As a result of the population growth of these areas greater demand can be expected on the health centers of; Eaglestone {Fishermead} ; Stantonbury {Giffard Park}, Bradwell Common {Heelands} and Two Mile Ash {Two Mile Ash}. All the recent housing has been constructed for owner occupation. In contrast, the central southern part of the new city,

incorporating Beanhill and Netherfield, has some of the oldest parts of the new city housing. These areas have the first rental housing for the new city. The review of the data on Milton Keynes suggests that the area of highest material deprivation exists in the south of the city particularly, the wards of Bletchley, Netherfield and Eaglestone. However, taking into consideration the low standards of living associated with retirement and older, deteriorating housing, these are found on the periphery of the new city, particularly in Wolverton. Despite the southern part of the city having the greatest area of deprivation, across all age groups, the greater numbers of community nurses and general practitioners are located in the northern part of the city.

IV Conclusions

This chapter has presented a review of the Oxford Region and the Milton Keynes District health policy aims and statutory provision. It has demonstrated the remarkable success which the region and the district have had in reducing expenditure and increasing hospital efficiency. The ORHA and the MKDHA are leaders in national policy for cost containment, hospital throughput, shorter lengths of hospital stay and a modest

increase in community versus hospital service expenditure. However, the overall expenditure of the Oxford Region is substantially less than other RHA's and its per capita expenditure is the lowest of all RHA's, the level of community nursing staffing is low despite the high rapid hospital throughput and shorter lengths of hospital stay. Within Milton Keynes, the distribution of community professional workers varies inversely with deprivation. Southern parts of the new city scored least well on the Jarman 8 scale indicating an underprivileged area, with a high general practitioner workload. It was this southern part of Milton Keynes which had the fewest professional staff. In addition, the commitment of regional and district health and community care policy is orientated to the care of the priority groups. It implicitly assumes that the priority groups are in greater need than patients discharged from acute care wards and it assumes that patients discharged from hospital do not have any particular needs once they have been discharged into the community. Nevertheless, Figures 3 and 4 show the large numbers of economically active and retired patients being discharged from general medical and surgical wards, with economically active patients exceeding retired patients, and males exceeding females. Current discharge policies assume that both the patient and the family are willing and able to cope. Furthermore, they assume that community professional services are adequate to cope with the demand from routine health care

demands , the care of the 'priority groups' and those discharged from hospital. The adequacy of current levels of statutory provision must be evaluated in relation to the composition and the expressed needs of those discharged from hospital. It is concern about the relationship between social structural characteristics and ill health, such as social class, occupation [or unemployment], age, sex and geographical location and about the levels of statutory support and the availability of neighbors which makes a small scale study on the discharge of patients so important. [Townsend,P. and Davidson,N. 1982, Goldblatt,P. and Fox,J.,1978, Jarman,B., 1983 and 1984.].

The next chapters turn to an examination of the people behind the statistics, follows them; in order to identify for 'whom' care is provided, 'who' cares for them, and the social , emotional and material costs of caring.

Chapter 5

The Social Demography of Care

A Survey of Forty Five Acute Care Patients

In this chapter, the sample of forty-five general medical and surgical patients discharged from hospital are examined in the light of the community care policy. Specifically, the chapter sets out to examine the implementation of current Milton Keynes district health care policy as it is reflected in the sample of 45 patients. It examines the lengths of stay, the diagnostic categories, and the social demographic characteristics of the patients. A few case studies are presented of both economically active and retired , male and female patients. These case studies illustrate the complex social and economic factors which are intertwined in patient after care. The case studies of the patients also illustrate the social and economic indices utilised by Jarman, as indicators of need in the community. Finally, the case studies indicate special needs of acute convalescent patients in the community.

I. Health Policy and Length of Stay

In the previous chapter the review of Oxford Regional and Milton Keynes District health policy identified a reduction in the length of hospital stay as a primary objective. The sample of forty-five patients reflected the trend of shorter lengths of stay in the Milton Keynes Hospital. The average length of stay was 7 days for both the retired and economically active patients. Tables 19 and 20 indicate the relationship between age and length of stay [Table 19] and diagnosis and length of stay [Table 20 and Table 21]. Table 19 reveals that there was only slight evidence of patients being kept in hospital for additional days due to age. This may partially be due to the fact that Milton Keynes District Hospital also has a geriatric ward which cares for the longer stay elderly patients. A consideration of Table 20 shows that comparing medical diagnosis and length of stay diagnosis is a more pertinent variable than age.

Table 19 shows that the majority of both economically active and retired patients stayed 7 days or less which reflects the district and regional trend for shorter lengths of stay. Of those patients who stayed on hospital longer than seven days, 8 to 10 days was the median number of days.

Table 19. Length of Hospital Stay and Age for 45 General Medical and Surgical Patients, 1986

Age	Number of Days in hospital		
	0 - 7	8 - 14	15 - 28
18 - 60 F/65 M [Base 25]	13	9	3
60+ F/ 65+ M [Base 20]	8	9	3
Total	21	18	6

From Table 19 it is evident that the elderly had only a slightly longer lengths of stay, with a median length of stay of 9 days. In contrast, the median length of stay for the economically active was 7 days or less.

Comparing the length of stay, of the 45 patients, with medical and surgical diagnostic categories, [Tables 20 and 21] shorter lengths of stay are evident in the surgical diagnostic categories compared to the general medical categories. The sample therefore confirms the trend of the MKDH for shorter lengths of stay, particularly in surgical wards.

Table 20. Length of Hospital Stay and Diagnosis for 45 General Medical Patients 1986

Presenting Complaint	0 - 7 Days	8 - 14 Days	15 - 28 Days
Cerebrovascular & ISHD	8	9	1
Respiratory	3	1	1
Diabetes	1	1	
Total	12	11	2

[* Presenting complaint = reason for admission]

Table 21. Length of Hospital Stay and Diagnosis for Surgical Patients, 1986

Presenting Complaint	0 - 7 Days	8 - 14 Days	15 - 28 Days
Gall Bladder	1		
Appendix	1	1	
Mastectomy	2		
Rectal			
cancer	1	2	1
inflammation	1		
Ileostomy			1
Hemorrhoids	1		
Hernia	1		
Tumour		1	
Multiple			
diagnosis	1	1	3
Unknown	1		
Total	10	5	5
Readmission	4		

[* Presenting Complaint = the reason for hospital admission]

A consideration of the diagnostic categories shows that cardiovascular illness was associated with a median length of stay between seven and ten days. The other single illness categories included respiratory disease , appendectomies , diabetes and "minor surgery", all of which, had an average length of stay of 7 days. However, in general, surgical patients had a shorter hospital stay than general medical patients, and as it was demonstrated in Chapter 4, surgical patients are typically younger than general medical patients. The shorter lengths of stay for younger patients is also reflected in Table 19. However, the five patients who were hospitalised for prolonged periods of time [15 days or more], were patients who had severe multiple health problems and this was not associated with age. Of the five patients, three

had major surgical operations and the other two had a number of major medical problems.

The incidence of particular diagnostic categories is also reflected in the sample. Ischemic heart disease and cerebrovascular illness were the predominant illness categories in the study. This is comparable to both national and district trends of a high mortality from heart disease. The OPCS data on general mortality rates by class demonstrate that mortality from coronary heart disease is one of the leading causes of death [OPCS, Health and Personal Social Service Statistics, 1986], Of the top 20 causes of death in Milton Keynes in 1985, ischemic heart disease and cerebrovascular disease are the leading causes of death, constituting 24% and 13% respectively. The fact that Milton Keynes has a high percentage of social class group III may well be reflected in the large number of people with heart disease in Milton Keynes. From a total of 22 male patients in the study, 12 had a cardiovascular diagnosis. Specifically, 11 of these men had a heart attack and 8 of these men were under the age of 60, [Table 22]. In contrast, from a total of 23 female patients only 5 had a cardiovascular diagnosis [including thrombosis, heart attack and arterial disease]. This reflects the national trend of higher rates of heart disease among men than women and the earlier incidence of morbidity and mortality among men. [Townsend, P. and Davidson, N., 1982]

II. Social and Demographic Characteristics of Patients

District health care reports on community care, have expressed concern over the social characteristics of Milton Keynes vis a vis other areas of the Oxford Region . Chapter 4 explored objectives of current district health policy in the light of the social and economic characteristics of the Milton Keynes population. Specifically, it considered the concerns of the Regional Health Authority over the social class composition of Milton Keynes, its' large new population, which lacks developed social networks, and the demographic structure of the new city. The review of district policy revealed that the hospital is pursuing a policy of discharging patients into the community earlier, however little consideration has been given to the social and economic characteristics of patients or 'who' they are or their needs, once they have been discharged. This is particularly important in the light of Jarman's work applied to Milton Keynes District Health Authority, which suggests that it could be considered 'an underprivileged area'. In order to provide a fuller understanding of the social structural and demographic characteristics of the forty five patients, Table 22 gives data on geographical locality, tenure, age, stage in the life cycle, and length of residence for each patient. The geographical areas listed also correspond to health center

areas in Milton Keynes.

Table 22. Social and Demographic Characteristics of Survey Group

Patient	Age	Marital Status	Illness	Econ Ac/ Retired	Tenure	Len of Residence
Stony Stratford and outlying areas						
Mrs. 1.	71	M	C.B	R	Owner	8 years
Mrs. 2.	43	D	C.B.	H	Rent	14 years
Mr. 3.	74	M	S	R	Owner	9 years
Mr. 4.	51	S	ISH	EC,II	Owner	20 years
Mrs. 5.	73	M	Res.	R	Owner	26 years
Wolverton						
Mr. 6.	83	W	M	R	Owner	Local
Mrs. 7.	63	M	S	R	Owner	Local
Mr. 8.	74	M	D	R	Rent	Local
Mr. 9.	89	W	M	R	Owner	50 years
Mrs. 10.	70	M	Res	R	Owner	Local
Mrs. 11.	56	W	S	EC,III	Owner	Local
Mrs. 12.	43	M	ISH	EC,II	Owner	Local
Mr. 13.	45	M	ISH	EC,III	Owner	Local
Mrs. 14.	50	M	Res	EC,IV	Owner	8 years
Mr. 15	47	M	ISH	Unemp	Rent	13 years
Newport Pagnell and outlying areas						
Mrs. 16.	76	M	S	R	Owner	10 years
Mrs. 17.	36	M	Res	EC,III	Owner	11 years
Mr. 18.	49	M	ISH	EC,III	Owner	6 years
Mr. 19.	51	M	Cancer	EC,III	Owner	6 years
New City Housing						
Mrs. 20.	55	M	C.B.	EC,IV	Owner	13 years
Mr. 21.	53	M	ISH	Unemp	Owner	8 years
Mr. 22.	59	M	ISH	Unemp	Rent	3 years
Mrs. 23.	76	M	S	R	Rent	5 years
Mrs. 24.	70	M	ISH	R	Rent	1 year
Mrs. 25	30	S	S	EC,III	Owner	5 years
Mr. 26.	58	M	ISH	EC,II	Owner	4 years
Mr. 27.	28	M	S	EC,II	Owner	7 years
Mr. 28.	68	M	M	R	Rent	2 years
Mr. 29.	67	M	S	R	Rent	6 years
Mrs. 30.	61	F	ISH	R	Owner	7 months

Mr. 31.	77	M	ISH	R	Owner	9 years
Mrs. 32.	47	M	S	H	Owner	8 years
Mrs. 33.	42	M	ISH	EC, IV	Rent	6 years
Mr. 34.	47	M	ISH	EC, II	Owner	15 years

Bletchley

Mrs. 35.	48	M	S	EC, V	Owner	Local
Mrs. 36.	55	M	S	EC, V	Rent	20 years
Mrs. 37.	59	M	S	H	Rent	Local
Mr. 38.	73	M	ISH	R	Owner	40 years
Mr. 39.	47	D	S	Unempl	Rent	14 years
Mrs. 40.	50	M	S	EC, V	Owner	26 years
Mrs. 41.	71	W	S	R	Owner	20 years

Woburn Sands

Mr. 42.	75	M	ISH	R	Owner	12 years
Mr. 43.	65	M	D	R	Owner	40 years
Mr. 44.	62	M	ISH	R	Owner	32 years
Mrs. 45.	46	M	S	H	Owner	14 years

Key:

ISH - Ischemic Heart Disease	EC- Economically Active
C.B. - Cerebrovascular Disease	R- Retired
D - Diabetic	H- Housewife
S - Surgery	M- Multiple
Res.- Respiratory	

I, II, III, IV, V - estimates of social class, by occupation of the patient; this does not accurately reflect the standard of living of some of the female patients, who earn less than half of their husbands.

Local- was born and lived in the area

Table 23. Social Class of Economically Active Heads of Household of Survey Group Compared to Milton Keynes

Occupational Group	HoH	%	Milton Keynes
I. Professional	0	0	4.9
II. Intermediate	5	20%	18.4
III. Skilled Non-Manual	6	24%	10.0
IV. Skilled Manual	3	12%	27.0
V. Semi-skilled	3	12%	11.3
VI. Unskilled	0	0	3.1
Inactive Heads	6	32%	22.9
Armed Forces	0	0	2.4
Total	25	100.0	100.0

[Inactive heads includes housewives who are HoH and Unemployed, HoH]

[Source: Health Means Milton Keynes ,District Profile, Information Unit, Dept. of Community Medicine, 1987]

An examination of Table 22 reveals that the patients in the sample broadly reflect the social and demographic characteristics of Milton Keynes. The table shows that the 45 patients roughly correspond with Milton Keynes residents by age, length of residence, and tenure. Table 22 reveals that in Stony Stratford, Wolverton, and Woburn Sands there were almost the same number of economically active and retired patients whereas in the New City and Bletchley economically active patients approximately doubled the number of retired patients. The large numbers of retired patients on the

periphery of the city reflects the age composition of areas within Milton Keynes [Table 17] with 35% of the elderly patients sampled living in Stony Stratford and Wolverton. However, the sample contained greater numbers of patients in the retired age group living in the New Town than is true of the available data from the Milton Keynes Household Survey of 1983. This may reflect the increasing numbers of elderly patients moving to Milton Keynes, by 1986, as the nature of the housing stock changes. By differentiating patients by their relationship to the economic structure, economically active or retired, also gives an indication of their stage in the life cycle, and attendant commitments. Analysing the social class distribution of the 25 economically active patients, only 5 were in social class II, 20% of the sample [Table 23]. The sample also contained a larger percentage of economically active patients in social class III, than the social class distribution of Milton Keynes and it contained less in social class IV [Table 23]. Social Class V was however a good reflection of the rest of Milton Keynes, expressed as a percentage. The larger number of inactive heads of household may reflect the close relationship between ill health and loss of employment.

The types of employment included industrial managers, librarians, teachers, secretaries and cleaners. Social class

is a weaker link among the retired, due to the levelling of retirement pensions. Nevertheless retired patients who had formerly held professional occupations, often had employment pensions, in addition to their state pensions.

Tables 22 and 23 reveal that the forty-five patients in the sample reflect a similarity to the socio-demographic structure of Milton Keynes and of hospital throughput. The sample, in general, reflects the trends identified in Milton Keynes by the Milton Keynes Information Unit research, using the Jarman indices. The sample reflects a mixture of newcomers and 'locals', 23 percent unemployed patients, a higher percentage in the lower socio-economic categories and a high proportion of owner occupation and the younger age structure of Milton Keynes. Considering one of Jarman's eight variables, length of residence, the index which most affects the Milton Keynes score, the sample includes nine 'locals'. From the sample of patients it is evident that the longest lengths of residence are in the older towns and these areas still have a large number of people who were 'born and bred' there. Wolverton and Bletchley have the largest number of 'locals' and the longer lengths of residence. Among the patients who lived in the new city housing the length of residence ranged from 1 year to 13 years , with an average of 5.6 years. This would substantiate the concern of health and social service planners about the newly developed areas in the new city. The

data also shows the high owner occupier rates for Milton Keynes , with the new population located primarily in the newly developed areas of the city. These characteristics suggest that the people in the new city, who are in the economically active age group and have the shortest lengths of residence, may have the least support from friends and neighbors. The fact that Milton Keynes and this sample, have a larger number of people in social class III and below suggests that patients are restricted financially, and by the fringe benefits of their employment.

The high owner occupier rate is recognised as a strength in Milton Keynes. Of the twenty retired patients 15 were owner occupiers and 5 rented their house. Of the seventeen employed patients only 2 [plus two housewives] rented their home, while 15 employed patients plus 2 'housewives' and their families, were purchasing their own home. Of the four unemployed patients, three rented their home and one owned his home.

III. The People behind the Statistics

To paraphrase C. Wright Mills, it is the job of every social scientist to seek to understand human variety in an orderly way, to integrate an understanding of biography and of history and of the problems of their intersection with social

structure.[Mills,C.W., 1959, p.148]

In a search to relate the statistics presented in the previous sections to the reality of everyday life for patients, the following section explores the people behind the statistics, to illuminate their individual biographies, and the implications of ill health in their personal lives. The case studies reveal the underlying social and economic forces and the interaction between material imperatives, family relationships and community ties.

Furthermore, the case studies establish patterns in this sample of male and female patients, stage in the life cycle and their relationship to the labour market. The case studies reveal both the commonality of the patients experience as well as the diversity of family circumstances.

A. Male Patients - Economically Active

One of the economically active male patients who had incurred a heart attack was Mr. Nollins [#26]. Mr. Nollins is fifty-eight years old and a father, of two teenage children. He and his family had moved to Milton Keynes four years ago when he had been offered a job in the city. The move to Milton Keynes provided an opportunity for further promotion in his

professional career and an opportunity to buy a new and larger house. Mrs. Nollins had successfully found a part time position as a manager in a shop in the new city, which suited her . They were quite happy with their move. Gradually they were making a few friends , although it was taking some time. Their goal was to complete the purchase of their new home before retirement. Suddenly, one evening, Mr. Nollins developed heart pains and suffered a heart attack. He was in hospital for seven days. The heart attack was a great shock to him and to his wife. He felt completely disorientated. The heart attack disrupted his concept of himself , his routines and his concept of the future. He also felt very conscious of the literature provided by the preventive health care movement and he felt guilty for having had 'bad' life style habits. Three weeks after his return home he found that he had been made redundant because of a recession in the industry. Mr. Nollins was understandably devastated. He was entirely dependent on his immediate family, specifically his wife, as other relatives lived far away. Mrs. Nollins was very worried about her husband, not only because of the heart attack but because it was compounded by the loss of his job. She decided that it was incumbent upon her to work full time, even though she did not like to leave her husband on his own during the day. The symptoms which Mr. Nollins had at the time of interview, were depression, anxiety to know if he was implementing his diet and exercise routines properly. He

wished to know if he was improving, and would have liked to have a health professional to monitor his well being.

Mr. Lambkin [#13], is another example of a young heart patient. He is a forty-five year old shop manager and has lived locally all his life with his wife and two teenage children. On the evening of the heart attack his wife called for an ambulance from her mother's house across the street. Mr. Lambkin was in hospital for seven days. Once discharged Mr. Lambkin had the companionship of his wife, his mother in law and his own relatives. This meant that his wife could continue to work in her part time job while her mother 'kept an eye on him'. For the first week, Mr. Lambkin felt very 'low' and he remarked on how glad he was to have the support of his family and not to be left on his own. He was not sure how much he should exercise and was constantly aware that another heart attack could occur. Although not a heavy drinker or particularly overweight he felt bad about the 'few pints' which he enjoyed from time to time and had resolved to watch his food intake. Fortunately, Mr. Lambkin was able to return to his job after eight weeks, without a loss of income.

Another example, Mr. Maple [#22] suffered a heart attack at the age of 51. Now , at the age of 58, he has had a third heart attack. As a result of his first heart attack Mr. Maple had lost his job. As his health progressively deteriorated,

employment was no longer a realistic possibility. His wife, has also not worked because she does not dare to leave her husband on his own. They have lived in Milton Keynes for a total of four years, although they recently moved to another housing estate. The family is dependent on state benefits for their income. At the time of the interview two of their six children were living with them. One of these sons was living there with his pregnant wife and child while they were waiting for a house to become available. Their other son was still in school. One other married son and one married daughter and their respective children also live in Milton Keynes. Frequently they were able to provide help. Due to the strong medicines that he was required to take, a nurse visited twice a week to perform a blood test to monitor medicine levels. Mr. Maple was the only heart patient who had a follow up from a community nurse. Nevertheless, Mr. Maple still said that he would like to have the twenty-four hour care of the hospital, although "you can't stay there all your life."

B. Male Patients- Retired

Mr. Brown [#6] is an elderly gentleman of 83 years who lives on his own. He is the classical example of old age and inability to look after himself. Hospitalisation was more a result of his inability to look after himself and the

likelihood of injuring himself as a specific illness. He lives in one room of his old house which has seriously deteriorated. Although he receives meals on wheels and home help, he does not always take the trouble to eat his meals. His elderly sister visits him twice a week to do his laundry and clean up a bit, however the inadequate plumbing, the damp and lack of good heating must make cleaning difficult. Fortunately his neighbor keeps an eye on him on a daily basis, checking that he has not fallen or that he eats some meals. Although a district nurse visits him twice weekly this intermittent care is not sufficient. Thus although there are a number of statutory agencies and friends looking in on Mr. Brown it is evident that he needs more support. He is forgetful, finds it difficult to conduct a conversation and is absent minded about eating and has fallen a number of times.

Mr. Smith [#8] is an elderly, but active person. He still enjoys gardening and chatting with his neighbors and going to the pub. He and his wife have lived in the area all their lives and in this particular house for over forty years. In hospital he was diagnosed as a diabetic and was told to monitor his own blood sugar levels and to go on a strict diet. The diagnosis of diabetes and the hospitalisation came as quite a shock to him. After discharge he kept very busy with his neighbors and helping them out, as he said "it helps to keep your mind off of it". He was upset that he may have

to give up his allotment which he had always enjoyed, because he found that he tired easily. Altogether, Mr. Smith had lost a stone since he went into hospital. However after discharge he found adhering strictly to his diabetic diet was difficult and occasionally he had 'a little extra' . The Smith's received little support from their children because they lived far away and they therefore saw little of them. Although Mr. Smith did not feel himself, in need of any statutory assistance, he may have benefited from the guidance and support for his diet.

Mr. Holmes [#38] lives with his wife in an older part in the south of the new city. He had a heart attack and at the time of the interviews he was evidently very depressed. He felt "obsolete" , and that time hangs on and is empty. His only child, a daughter lives some distance away with her husband and child . His daughter and her husband both work full time and lead a busy social life and consequently they could only visit occasionally and provide practical or emotional support. Mr. Holmes was unable to drive since the heart attack and was most appreciative when a neighbor took him to have his hair cut. However his main preoccupation was that 'my doctor is responsible for my health' and ' its up to him to get me well again'. Mr. Holmes was out of hospital only two weeks when he suffered a second heart attack and was in hospital for a further seven days. At the time of the second interview he

was very depressed and anxious with no statutory support.

C. Female Patients-Economically Active

Mrs. Cose [#35] had been suffering from gall stones for sometime and this had affected her appetite and digestion. Mrs. Cose had been on the waiting list for surgery for some time, but she had been dreading being called in for surgery. She feared hospitals and viewed them as a place where people often died. She therefore was pleased to return home. However, after discharge Mrs. Cose felt very unwell at home, very low emotionally, weak physically and still experiencing considerable pain. Her husband is a shift worker and he could not take time off work to look after his wife without losing income. The major responsibility devolved to her married daughter despite the fact that Mrs. Cose's son, of 23, still lived at home. Her daughter took several weeks off from her part time employment to care for her mother, although she lost income as a result. Her daughter prepared the meals, washed, ironed and cleaned for the household and looked after her own household, her husband and two small children.

Mrs. Cat [#36], in contrast, had an emergency surgical operation. She was in hospital for eight days. She lives with

her young daughter, her husband and elderly father and normally cares for them all. Before the operation Mrs. Cat also worked part time. However due to her illness and the convalescence she lost some income. In order to look after her, Mr. Cat was able to take one week off from work, although as a result of this he lost income too. He therefore was unable to continue staying at home to look after his wife although she was still experiencing considerable pain and lack of mobility for several weeks after her operation. It was only after six weeks after discharge that she was beginning to 'get back to normal'. Her husband had however, cooked the meals and did the housework when he returned from work. Her 'grown up' daughter, who lived near by came over to do the ironing and a 'few bits and pieces', jobs her husband would not do.

Mrs. Fall [#45] lives with her husband and three teenage children in a nice home on periphery of the new city. As a result of her operation several months previously she left her full time job. At the time of the interview she was recovering from her follow up operation. At the time of the interviews she is confined largely to the house until the wounds heal. She spends much of the day on her own as her husband is at work and her children are at school. Although Mrs. Fall felt her neighbors were helpful she felt the lack of medical advice and expertise. She said " There seems to be a lack of communication between the G.P. and the patient when you come

out of hospital . They don't know how you are getting on." She was feeling low, still in pain, uncertain of the prognosis and unsure if the wounds were healing satisfactorily.

Mrs. Hunter [#37] has recently had a mastectomy for cancer of the breast. She was , up until her illness, an active 59 year old living with her second husband. Her husband, although retired , worked part time and is active and fit. Mrs. Hunter had worked as a volunteer in a local organisation and occasionally did part time work . She has lived in the Milton Keynes area all her life. One of Mrs. Hunter's daughter's lives locally, and temporarily moved in to her parents home to help in the house while her mother was recuperating. Her other daughter lives forty -five minutes drive away and could only visit at weekends. Her son lives with his natural father. Mrs. Hunter was experiencing a great deal of difficulty with the suddenness of the operation and the necessity for follow up radium treatment." The thing was that I felt great before I went into hospital. It all came as quite a shock. I feel fine now, it's just that I don't know if it is normal to feel this way after an operation such as this . I have soreness and a puffy feeling under my arm. I don't know if this is normal after such an operation or not. I am so upset that I forgot to ask the consultant when I went last week." Mrs. Hunter was clearly still acutely anxious about the prognosis. She was in

a state of shock at the rapidity of the diagnosis, the operation and the discharge. Although she had considerable support from her daughters and a friend she primarily wanted reassurance from a doctor.

D. Female Patients- Retired

Mrs. Vassar [#5] is an elderly widowed lady who suffers from chronic respiratory problems, and hospitalisation occurs from time to time when breathing becomes particularly difficult. She has lived locally all her life. For the last eight years she has lived with her 58 year old married daughter, her daughter's husband and their teenage son. Her daughter took on the responsibility to look after her mother some years ago when the asthmatic attacks became so acute that her mother was often up at night and occasionally incontinent. However, in recent years the strain of looking after her mother and working part time became too demanding and Mrs. Phillips decided to quit her part time secretarial job. Mrs. Vassar appeared to take her daughter's caring as her natural due. For the most part her life was confined to a chair, because mobility accentuated breathing problems. Her daughter collected her medications, bathed her and helped to dress her and prepared all her meals.

In contrast, Mrs. Olfman [#23] is a 76 year old , active and alert lady who had undergone major surgery. As a result of the surgery she was largely confined to her chair during the day and she found movement of any sort most painful. However she did spend some time each day reading, knitting or writing. She and her husband had moved to Milton Keynes recently to be near their son. However he subsequently moved to another part of England as a result of a promotion. They therefore saw little of him. Their daughter also lived far away, thus Mr. and Mrs. Olfman were left without any children locally. Mr. Olfman cared for his wife, and began to learn to cook during this period 'a little more than an egg or some bacon.' He had an occasional Sunday commitment to deliver a sermon, however their outside obligations and commitments were few. They lived in a small group of houses constructed for elderly persons. This they felt had advantages and disadvantages. It was unpleasant living with all other people in varying degrees of ill health, although it did make for a quiet area, with a degree of neighborly support. Thus while they lived in a supportive community, the people also had infirmities and were limited in the help they could provide. Mrs. Olfman was still in a great deal of pain after discharge. Some two weeks after her discharge she had caught a throat infection which weakened her and she was unable to easily get rid of it despite having visited the G.P and having been given some antibiotics.

Mrs. Compton [#30] is a newcomer to Milton Keynes with her husband. They had lived in London and upon retirement they had decided to move to Milton Keynes to be near their son and to buy a house. Approximately, nine months after moving in Mrs. Compton had a heart attack. After discharge she gave up cigarettes but she continued her normal energetic life; dusting , hoovering and cleaning up after the building work. Due to their recent move to Milton Keynes and all the redecorating work which they had undertaken she did not know her neighbors. She thought that they were predominantly working couples. Her son, daughter-in-law and granddaughter fulfilled, at least temporarily, her needs for companionship and assistance. She was not apparently in need of medical or social service assistance.

E. General Characteristics of Patients

It is evident from the descriptions of the patients and their home circumstances that there was considerable variation in health status, social circumstances , occupational security and employment benefits. The interplay of these factors affect the single or multiple dependencies which the patients have and the social circumstances of the family. It is clear that the relationship between 'medical' and 'social' needs are

often an arbitrary distinction. The case studies outline and illustrate the interplay of individual life styles, structural forces and the role of the family in caring for its members. All of these patients have in common an attempt to cope with a crisis in their lives. It is at the same time a medical crisis, and a social crisis. Each of these acute conditions brings with it multiple problems in living. The most pressing problems are preventing and managing medical crises, managing regimes, controlling symptoms, organizing one's time efficiently, preventing or living with social isolation, adjusting to ill health and normalizing life. It is evident from these case studies that acute ill health and chronic ill health are social events and not only medical ailments. They are identified in a social context, mediated in the family and in turn influence the shape and ability of the family to function. Health related problems are created by the change in role and performance levels of an individual to function within the family. A patient returned to the home may suffer role destruction and adjustment, stigmatization, loss of mobility, and a renegotiation of roles within the family; as in the cases where patients have lost their employment.

The case studies reveal trends in community care of convalescent patients. The impact of caring for a convalescent patient on the family falls into two broad categories; those associated with employment and direct economic costs and

those associated with less tangible, but nevertheless significant social 'costs'. The direct and social costs are exacerbated or ameliorated by the social spheres in which the patients live. These social spheres are related to length of residence , age and availability of neighbors and social class.

By distinguishing between economically active and retired male and female patients an attempt has been made to delineate characteristics of these respective groups. It seeks to identify the relationship of the family to the broader social structure. Retirement and old age are as much a product of declining abilities as it is a relationship to the economic and social fabric of society. For the most part 60 / 65 year old women and men no longer participate in the labour force and rely on the state or past employment for their income. It places these groups outside or on the fringe of society. Time and social obligations often change dramatically as well as material standards of living after retirement [Abrams, P., and Brown,R.,1987 and Graham,P., 1987]. This directly influenced the structure of their daily activities and levels of involvement in the community. In contrast, the economically active population are expected by the family and society to work either within the family or in the labour force to provide financial responsibility for the family. The ability to do so is hampered or impaired due to ill health ,

either temporarily or permanently. The division of labour within the family is typically more strictly divided in this stage of the life cycle. The 'natural' caring function of the wife , including her degree of commitment to employment and her 'automatic ' ability to perform many tasks within the household often direct her into a caring role.

It is striking from these case studies the number of retired couples who moved to Milton Keynes to be with their married children. The necessity to be geographically mobile to obtain employment and housing increasingly results in 'elderly' parents moving to be close to their married children and grandchildren. It is also striking to note in these case studies, the close mother-daughter relationship in care giving in both the retired and economically active age groups. The most isolated categories are those in the economically active age group with teenage children and elderly single males.

A consideration of the health status of patients once they have been discharged from hospital indicates a considerable responsibility on the part of the family to provide both medical and welfare skills. The health status of patients after discharge varied somewhat with the nature of the illness. Heart and surgery patients could be distinguished as those experiencing the greatest pain, discomfort and insecurity after discharge. However, one week after discharge

all of the patients were still experiencing pain and lack of mobility. They were in a fragile condition not only physically but also many expressed feelings of depression and anxiety. Table 24 shows that the majority of patients are still experiencing pain, lack of mobility and depression five to six weeks after they were discharged.

Table 24. Patient Well Being

The Degree of Patient Well Being [5 - 6 weeks after discharge]

Patient Experiencing	Pain	Depression	Lack of Mobility	Incontinence	None
	25	20	20	3	9

Note: Patient Well Being is based on self assessed definitions of pain, depression, mobility and incontinence.

* Mobility was assessed on the basis of patients being able to perform daily household tasks such as; cooking, cleaning, bathing] Necessarily , patients perceived their level of capacity in relation to their abilities prior to hospitalization.

* 'Depression ' was rated either through self appraised depression or because the patient was not sleeping or was taking valium.

Table 24 indicates that many of the patients are suffering from one or more symptoms six weeks after discharge. Most of these patients are confined to their homes and spend most of their day in a chair. They are largely dependent on their spouse or other relative to provide them with routine daily tasks, personnel care, companionship, to monitor their health, to supervise their medication, diet and exercise; to evaluate

when professional assistance is required and arrange the transportation and appointments for professional appointments. They were, in other words, very dependent on another person being available to provide this care. Patients who felt particularly vulnerable, such as those who had major surgery, or who had a heart attack felt a lack of confidence in their body. They frequently expressed the wish for medical follow-up and reassurance. This was particularly the case for the younger age groups. They were unprepared for their recent illness. They did not perceive themselves as 'being old'. In contrast, older patients appeared somewhat more resigned to their situation. Mr. Nollins, an economically active patient said "I would like a follow up from a professional [doctor] to reassure me and to give me advice on how I'm doing; if I'm taking enough exercise and on my diet". In contrast, an elderly lady, of 70 years, said "I went into hospital to have a pacemaker put in." She was unsure of her diagnosis and did not express any particular interest. When asked about her medication she said that she takes some tablets but she was not sure what they were for. "I take two types of tablets, one set of tablets are for 'water', but I think they make me a bit incontinent and I think that I take blood pressure tablets, but I don't know." Many other patients expressed the wish for the authority and twenty four hour care which a hospital provides. One of the patients expressed it quite succinctly; "In hospital you have twenty four hour care; in

hospital people know what they are doing ; they relieve you of responsibility; which is beneficial because it relieves you of anxiety".

While all the patients experienced anxieties, problems with mobility exacerbated the problems which they already felt. The lack of mobility for many of the patients meant that their daily routines were restricted and role relationships were changed and this compounded their depression. This is exemplified by Mr. Nollins , who was made redundant and his wife took it upon herself to work full time. He said "Now, I'll be doing the shopping and cleaning , I'll be like a woman at home". The current reversal in circumstances was threatening not only family income but also his perception of himself as a man and as his role of breadwinner for the family.

For those patients with restricted mobility practical tasks were also a problem. One of the problems which was mentioned with embarrassment was the need for a bath. Patients who lived in two storey houses, with upstairs baths, often only managed the stairs once a week. Other patients found that without a bath rail they could not manage a bath. It was a mundane problem which carers did not even seem to know how to overcome. The task of obtaining and installing a bath rail remained a lingering problem in the eyes of patients and

carers.

Several of the patients needed assistance with walking of any sort. This involved the spouse or other relative to walk with them to the bath room , help them get dressed and undressed, to bring them meals to their chair, to bring them to bed and to accompany the 'patient' at all times. This is particularly difficult for spouses who are elderly themselves or weaker or smaller than their spouse or relative.

IV Conclusion

In conclusion, in this chapter it has been argued that the sample of patients broadly reflect the general medical and surgical patients in Milton Keynes. They reflect district policy of shorter lengths of stay, and the trends in Milton Keynes in, major diagnostic categories, age, sex, length of residence and to a certain extent the social class structure. Furthermore, it has been argued that the needs of discharged patients have show a great deal of similarity. The majority of patients experience pain, lack of mobility and self identified depression. Despite the similarities in patients needs, the case studies reveal the diversity of family circumstances, to which patients are returned after discharge. The diverse family circumstances reflect characteristics which

are particular to Milton Keynes, as well as broader national and regional trends, in unemployment, family structure, and the relationship between ill health and social class. The case studies also suggest the emerging themes of convalescent care in the community; the convalescent career , 'who' cares and the nature of community care.

Chapter 6

The Convalescent Career

Acute ill health marks an embarkation on a career which commences in pain, is hallmarked by the entrance to the hospital, where medical professionals diagnose, legitimize and arbitrate health status until they authorize the patient's discharge from hospital. The discharge from hospital signals the end of the acute phase of ill health and it marks the beginning of the convalescent career. It is the moment when the family becomes the provider, the negotiator and the mediator of health care. It is at this stage that levels of medical knowledge, stage in the life cycle, material constraints and lay health beliefs affect the ability of the family to provide health care.

This chapter examines the convalescent career, the stages it marks and their characteristics. The concept of the convalescent career unifies the individuality of the experience of ill health with institutional and structural characteristics associated with the hospital and the family.

I. The Admission to Hospital

The admission to hospital marks an abrupt shift in the patterns of daily life. In this sample, all the patients went into hospital for either emergency or prescribed treatment. None of the cases were 'elective'. The only patients who entered hospital with a prearranged appointment were the hernia and gall stone operations. Appendix operations are typically 'emergency cases' and the heart attack and related cardiovascular patients also typically entered hospital as emergencies. Thus the majority of patients entered hospital unexpectedly. The emergency nature of most medical and surgical admissions is a traumatic experience for the patient and the family. It instigates a career composed of the progressive changes that occur in the beliefs that patients have concerning themselves and significant others. Characteristically, acute ill health is sudden in onset, it weakens the body and demoralizes the self. The rapidity, the pain, and the uncertainty of the diagnosis bring the patient to hospital. It is a decision that the family have made with or without the advice of the general practitioner. The family can be critical in deciding to bring the person to the hospital. The example of Mrs. Kay [wife of patient #43] illustrates the crucial role the family can play in deciding to bring a family member to the hospital. In their case, the general practitioner had not made an accurate diagnosis and it was Mrs. Kay who realized that her husband was slipping into a coma from diabetes. She ordered the ambulance to bring her husband to the hospital in the early

hours of the morning . However, in the cases of other patients the symptoms were less clear cut and family members called the general practitioner to have a decision made about the appropriate course of action. Admission procedures, such as taking information on the patient is the beginning of the procedure of changing the new entrant from a person to a 'patient'. The patient is subjected to various procedures in order to identify and diagnose his pain , locate the malfunction and to provide a medical category which suggests the appropriate course of treatment. These procedures, are based on medical authority, expertise and are bound and shrouded in a medical aura. During the process of 'becoming a patient' a person loses their identity, normal roles, along with personal belongings, and rights to self determination. However, the admission to hospital is also the moment when patients expect relief from acute pain and anxiety, as they give themselves over to the professional staff in the hospital.

II. The Discharge from Hospital

The return home is heralded as a declassification from their acutely sick role to one of convalescence. It is the moment which, in hospital, patients look forward to. They look forward to 'being better' , to sitting in the comfort of their own surroundings and at least a partial return to the normal roles and status within

the family. It is regarded as a rite of passage from an acute state of ill health to convalescence. As one patient said " I think that in hospital you feel ill still, even if you are getting better. When you get out [of hospital] you feel a lot better- you feel like you are taking a label off." [patient # 25]

Returning home is also a return to a degree of autonomy and liberty which in the hospital is determined by the exigencies of the professional work schedules and other hospital personnel. The exit from hospital signals the transition from professional care to lay care. The patient must become responsible for their medications, new health care procedures and to evaluate their own health. It marks the shift from a classical pattern of health care management which has specially devised procedures which will cure or control the complaint to one of domestic self management, based on lay knowledge.

A. First Week Post Discharge

The first week home is an unexpected, traumatic experience for patients and their families . The home which such a short time previously had been an orderly , routine existence is disrupted. The first week home patients are trying to define, comprehend and interpret their experience. It is a period of acute anxiety. In the hospital, the reassurance of the medical staff and the commonality of ill health normalised the experience somewhat. The

illness marked a crisis in their life which was brought more sharply into focus on their return home. The illness brought in its' wake an uncertainty of what had been perceived as a predictable future. The suddenness of the experience, the disorientation of hospital and the return home changed their concept of the past , the present and the future. Furthermore, the inability to perform normal roles and the dependence on a carer changed their everyday world. Their everyday world had to be reconstructed. The illness therefore not only represented a medical experience with surgical or bio-physical intervention, but it was an individual and a social experience. The threat to the construction of their own identity was profound. It created a feeling of the separation of the body and the person. The body became perceived as an entity distinct from the person. It created a discontinuity between who they were and what they could do and who they could be. The temporary or permanent loss of physical ability therefore created a disparity between their physical self and their perception of themselves. This threat to their identity brought about a review of the values in their life. It was formulated in a questioning of the meaningfulness of life. The profound and occasionally philosophical questioning often took the form of alienation . Feelings of hopelessness and detachment were often expressed. As one patient said, " I feel obsolete, redundant." [patient #42]

Another patient and her spouse said, " You work all your lives,

but for what?" [patient # 12] They discussed giving up their jobs and moving to the countryside. This couple wanted to try to find a more meaningful style of life.

Some patients took a fatalistic approach, while others, felt 'morally culpable' in response to their illness. For younger patients it precipitated a mid-life crisis. They felt that it marked the transition between being middle aged and being old. Their body was telling them to slow down. It made them reflective. They felt that their children were growing up and that in a few years they would be retiring and disengaging from roles which they had fulfilled for many years. Older patients, in contrast, had already undergone these role disengagements and had often experienced minor episodes of ill health. Over the years they had been experiencing the gradual lessening of mobility. The recent illness and the lack of mobility therefore often did not present as sharp a contrast in their level of overall functioning. However, for all patients the recent episode brought home sharply the threat of death. As one patient said ;

" I've had it worked out to pay off the mortgage in the next two years, so that I could leave it to my wife and kids. But now that I've lost my job I don't know whether this will be possible."
[patient # 26]

The potential loss of a life-long partner also instilled a fear in

many spouses. This was often reflected in the feeling that providing enough rest, a good diet and concern were not enough. The disparity between their concern and their medical knowledge made them feel inadequate to the task of caring.

The re-evaluation of life was combined with attempts to test physical limitations and to learn to implement new medical regimes. Some patients began writing lists of their tablets, their diet and their physical exercise. However, at the time of discharge and for many patients six weeks later they were still suffering from lack of mobility and depression. Table 25 gives a comparison of the progress of patients over the six week period and it compares the results with Hunt's study of the 'elderly at home.'

The sudden and dramatic separation from the security provided by the hospital and the lack of a visit from their general practitioner left an unfulfilled gap. Patients frequently expressed the wish that their general practitioner would visit them. On discharge from hospital, patients were given a discharge note which they were asked to take to their general practitioner. This is the primary method used to notify the general practitioner that the patient had returned home. In some instances the hospital notifies the G.P. directly of a patient's discharge. Nevertheless, patients occasionally said they were unsure whether their general practitioner even knew that they had been discharged. This was particularly, if the discharge note had been dropped off or posted

to the health center. For many patients, the discharge note served as a legitimating reason to make contact with their doctor. It also, typically contained a new prescription for medications. Although most patients visited the health center, in some cases they asked their spouse or another family member to make this trip. Occasionally the physical limitations created by surgery combined with the lack of an automobile made it difficult, if not impossible, for the patient to go to the health center. Heart patients were not allowed to drive a car for at least six weeks post discharge due to insurance company policy. The majority of patients however made a trip to the general practitioner, at least once and in some cases several times, during their convalescence. Patients wanted their general practitioner to know they were home and they wanted to ask questions which were still worrying them. These questions were of both a medical and a social nature. They wanted to know the answers to 'medical ' questions such as appropriate levels of exercise, concerns about the tablets. They were particularly worried if the tablets were creating unpleasant side effects, or if they were supposed to decide the appropriate use of self directed tablets, such as the heart tablets for the reduction of heart palpitations. Patients also wanted to ask questions about their future prognosis, whether and when they could return to work, when they would be able to walk to the shops again and when the general practitioner thought they would be 'back to normal'.

These questions stemmed from the realization of the possibility of

mortality, a fear expressed by the patient and their spouse. Frequently, the main carer contacted the general practitioner, but this was often far short of the number of times they felt the need to contact him. The identification of symptoms was continually being evaluated in relation to the trouble it would create for the doctor and their perception of its' legitimacy in the perception of the general practitioner. Although many discharged patients would have liked home visits they felt that few of the health center doctors in the new city would make house calls. As one patient, who lives on a new housing estate said;

"The doctors and nurses from the health center don't come to the house if you ring up and say that you don't feel well.

They tell you to take two aspirin and go to bed." [he was however visited by a hospital community nurse twice weekly] [patient # 22].

An awareness that lay concepts of health care are based on 'common sense' explanations as well as the awareness of their own lack of medical knowledge, quickly makes patients and their carers anxious. This is exemplified by a sixty year old lady's comment, but it was reiterated by many other patients.

" In hospital they have the expertise, and at home we feel the lack of experience." [patient #30]

Patients expressed feelings of abandonment by the medical

profession. As one patient said;

" You are discharged and just left to get on with it, I mean things could be really terrible at home and no one would know".[patient # 45]

The relationship with general practitioners varied between patients and G.P. practices. However, most patients were reluctant to contact their G.P. often, with the awareness that they were busy and had many demands on their time. Nevertheless, the comments from patients consistently pointed to a desire for greater G.P. interest in their after care. One elderly patient commented;

" I think that they have an obligation to come here [to the home] if you are over 80. Two or three years ago I had a district nurse. I think that the services have almost faded out. It is a twenty minute walk for me, even the secretary said that the G.P should come and visit me." [patient # 9]

This is despite the fact that general practitioners derive extra income for paying house calls on patients over 80 .

The three patients who were followed up by their G.P. and had home visits did not realize that they were the exception. They appreciated the G.P. home visit. These patients were not in greater ill health or less mobile than other patients. They were fortunate to have a G.P. who made an effort to do home visits.

B. Six Weeks Post Discharge

The six week follow up interview showed a considerable improvement in the majority of the patients, however many patients were still suffering from lack of mobility, and depression [Table 24]. By this time, most economically active carers had returned to work and therefore patients were left on their own all day. By six weeks after discharge, contact had been established with either the hospital consultants, general practitioners or nursing staff.

The six week interview illustrated differing health outcomes and the role losses which were often associated with an episode of ill health. Six weeks after discharge patients had in most instances improved. They were no longer experiencing the same degree of pain. They were for the most part somewhat stronger and therefore increasingly capable of resuming some of their normal routines. By six weeks post discharge the regimes of diet, medication, and exercise had gradually been implemented and routinised to a greater or lesser extent. Personal care for most patients had become easier, although difficulties remained with some household tasks. Shopping and 'going out' were still too difficult for the majority of patients [Table 25]. The prolonged restriction of mobility, the threat to their identity and, in some cases, the loss of roles, led to a loss of interest and self esteem. However, for many economically active patients 'absolution' from outside responsibilities and duties was drawing to a close. The 'sick

leave', had almost expired and patients were forced either to ask their general practitioner for a 'new sick note' or to return to work. Many of the economically active patients were gradually resuming work on a part time basis. During the course of the convalescent period some patients found that their employers were no longer able to employ them. Patients who lost their jobs usually found out around the third or fourth week of convalescence. For these patients the ill health episode represented a double loss. It threatened their identity ,their income and their future. It was a double loss, the diminution of health and the loss of a fundamental responsibility for the maintenance or contribution to the family income. Frequently the doctor was contacted to discuss the problem and to offer medication for these social problems. The acute depression which followed the news of a job loss accentuated already existing feelings of depression. From the sample four patients lost their job . These four patients had therefore not only experienced an episode of acute ill health, a temporary or permanent threat to their identity but also suffered role loss which potentially threatened the financial well being of the family.

These patients were threatened not only by a temporary loss of status but faced with the possibility of a permanent role loss. This was particularly acute for men who had traditionally seen themselves as the main breadwinner. It was clear that for the men who had lost their employment there was no counselling service to

help them to discuss their problems. One patient took his worry to his local general practitioner.

He said;

" I'm going to see my doctor next Tuesday. I would like to talk to him about my future - I'm out of work and I want to ask what my future holds." [patient #21]

Among the retired couples recovery often seemed to be slower and this combined with lower levels of mobility meant that outings were less frequent, although some patients had resumed light gardening, or housework. Table 23 provides an illuminating comparison of patients using Hunt's categories of Activities in Daily Living. The ability of patients to perform daily tasks can be compared to the first week post discharge and six weeks post discharge and to Hunt's study of the 'Elderly at Home'. The data indicates that those discharged from hospital are less mobile the first week after discharge than the 'elderly at home', in Hunt's study. Although there is a significant improvement six weeks after discharge, 13 per cent of patients still needed help with a bath, 31 per cent need help going out of doors and 15 per cent need help going upstairs.

Table 25 shows that even six weeks post discharge, fewer patients 'can manage without difficulty ' than the elderly at home. Only 30% of the patients could go outdoors, 62% could have a bath without difficulty and 48% could go upstairs without difficulty at

six weeks post discharge. These figures suggest that a large percentage of patients still require some kind of assistance six weeks post discharge and are reliant on the availability of family members.

Table 25. Comparison : Capacity for Daily Living; 'Elderly at Home', 1 Week and 6 Weeks Post Discharge.

Ability	Feed one	Bath one	Get around	Go out doors	Go up stairs	Gardening
Can Manage without Difficulty						
Hunt	96.6	73.1	88.7	75.6	66.9	43.2
Acute Care						
1 week pd.	99.0	28.8	20.1	4.5	20.0	0
6 weeks pd.	99.0	62.5	80.1	29.8	48.8	15.5
Can Manage with Difficulty	Feed one	Bath one	Get around	Go out doors	Go up stairs	Gardening
Hunt	2.1	11.1	9.6	11.5	27.0	14.1
1 Week pd.	1.0	44.0	57.7	40.0	33.3	----
6 Weeks pd.	1.0	22.2	17.7	22.5	24.4	----
Only with Help	Feed one	Bath one	Get around	Go out doors	Go up stairs	Gardening
Hunt	0.7	6.6	0.6	6.5	2.4	4.1
1 Week pd.	----	22.2	22.2	35.5	11.1	----
6 Weeks pd.	---	13.3	2.2	31.5	15.5	----
Can not Manage	Feed one	Bath one	Get around	Go out doors	Go up stairs	Gardening
Hunt	8.3	1.0	5.9	3.5	12.9	20.5
1 Week pd.	---	2.0	0	20.0	35.6	---
6 Weeks pd.	----	2.0	0	16.6	11.3	----
Totals						
1 Week pd.	100	100	100	100	100	---
6 Weeks pd.	100	100	100	100	100	---

[Source: Hunt, A., The Elderly at Home, 1978.]

- * Gardening was not specifically asked, however for patients who found that going out was too difficult it could be assumed that gardening would be too strenuous
- * Not all patients had stairs in their homes.
- * Hunt's study had also asked whether people could cut toe nails.

Patient accounts of the first weeks home was particularly heart rendering because, despite the anxiety, the fear, and the uncertainty, patients often said how lucky they were. Many patients said;

"There are many people who are far worse off than I am."

[patient # 25]

Thirty-three of the forty-five patients had a six week post discharge appointment with the consultant. The patients looked forward to this appointment. The visit was a forum for patients to ask questions. The consultation also provided them with the setting to remove the sense of pervasive isolation of their experience. The realization that other people were experiencing similar sorts of problems, undergoing similar pains, depressions and fears, normalised their own fears. The visit also enabled patients to realise that their health was gradually improving over the six week period. It was viewed as a progress report. The questions which patients wanted to ask at this visit shifted from the causes of ill health, to how to maintain their health. They wanted to be able to assess how well they had progressed over the six weeks. It was also the case that many patients forgot their questions while they were in the consulting room and they were therefore still plagued with unanswered questions when they returned home. However, the six week follow up visit came at a time when for many of the patients there was some lessening of

anxiety. The disjunction which patients had felt between their body and themselves, which had been evident in the first week, was not so apparent. Improvement in mobility and the reduction in pain improved their sense of well being.

However, not all patients were so fortunate, as Table 25 indicates. Some patients were still confined to their homes. A few had made tentative trips out but had found the experience too painful and were very dismayed. In addition , a few patients had suffered complications or minor infections 'which set them back.' They were struggling to believe that their health was improving, but the prolonged confinement to the home and the lack of variety and made them depressed. The anticipated improvement had not been fulfilled or at least was very slow in being realised. These patients had often had to contact their doctor. Examples of the set backs or complications were sore throats, infection in wounds, and readmission for the same problem or a complication thereof. A number of patients had wound infections such as in the small incision for the implantation of a pace maker. However, one appendicitis patient [#3] had quite a severe infection. Patients found these minor infections upsetting and praised themselves for knowing how to cope with minor infections. However, in the case of the infection of larger incisions patients called the doctor to look at it. Patients felt that they had been doing everything that could be expected of them yet they had these set backs. Four patients were readmitted to hospital. Mr. Williams [39] had to

return to hospital for rectal surgery and Mr. Phillips [38] had suffered another heart attack and spent another five days in hospital. Mr. Brown [#6] was readmitted, but this time to the geriatric ward. Mrs. West [#1] was readmitted due to a pulmonary complication.

While the majority of patients had a person with them at home for the first week after they were discharged, this changed among economically active carers in subsequent weeks. The fact that many of the main carers had returned to work meant that among the economically active age groups patients were isolated for prolonged periods of time. For the patients who were improving this did not affect them particularly, but for patients who were still largely confined to the house, with only the T.V and the radio for company, it was a very depressing experience. Prolonged isolation, the inability to perform useful activities and the uncertainty of the future made for feelings of a certain futility of existence. As one patient said ;

"I try to keep myself busy, by reading or writing but I have been accustomed to a very active life by helping others." [patient # 23]

The lack of fulfilling a useful role in the family or to the community was an aspect of convalescence which patients felt very quickly. They felt themselves to be a burden to their family.

While it was certainly the case that most of the carers provided the most love and attention which they could provide, either through their own efforts or by obtaining assistance, there were also times when the relationship was strained. Once the initial anxiety over the patient was overcome, interpersonal problems occasionally arose. Carers or relatives think that the patient is being self centered and pre occupied with illness and patients think that their spouse does not really understand the experience at all. This was expressed by feelings of resentment that the carer could not really understand how the patient felt. The relationship was strained, in a few cases. This was reflected in a remark that was intended to be light hearted but it belied some real problems. As one husband said;

"You can tell she is getting better, we're quarrelling again"
[patient # 32].

Among a few couples, there were instances of resentment that the main carer was not taking enough interest or showing much concern. The patient already feeling isolated and anxious was not getting much attention from their spouse. In those cases where this was due to legitimised reasons , such as work, it did not appear to cause resentment . Resentment appeared to creep in where the spouse did not absolve the patient of certain normal household tasks and did not alter their pattern of living to account for the episode of ill

health. As one male patient said;

"She's checking out the life insurance policy! I'm doing all the cooking and looking after my daughter, in fact I'm doing more now that I am at home than I did when I was working." [patient #18]

III Conclusion

Patient comments illustrate the original purpose behind the original conception of the community care policy. Care in the home is seen to be more personal and more comforting and therefore conducive to recovery and well being. However these interviews also show the problems of convalescent care in the home. The interviews demonstrate the difficulties associated with the transition from hospital to home, and changes over time as well as problems with convalescent care.

The interviews demonstrate the central tension between the nature of the care in the medical , authoritative, experienced environment of the hospital and the lay care in the home. Patients were aware of the lack of experience, and knowledge. All the patients experienced subjective and objective changes in health concept. The ensuing weeks post discharge were difficult. Adjustment was a period of acute anxiety, which involved gaining knowledge,

implementing care regimes, dealing with anxieties, and coming to terms with a 'new self'.

The convalescent career demarcated the entrance and exit from hospital and the gradual process of restoring health. The concept of the convalescent career unifies the individuality of the experience of ill health with the social and economic context. This is particularly important in the case of community care of convalescent patients. It places ill health on a continuum of recognised ill health, hospital discharge, convalescence and health outcomes. The concept of a 'career' incorporates structural constraints and it emphasises individual responsibility, action and initiative.

It is argued that the difficulty with transferring patients from the hospital to the community is reflected in the geographical, institutional and organisational differences between the hospital and the home environment. The transfer of patient medical information between the hospital and the health center relies on the individual patient to transfer information between the hospital and the general practitioner. It relies on the patient to transmit the medical knowledge and discharge information to their doctor. A potential communication gap exists here in some cases as some patients are unaware of the exact nature of their diagnosis, their medications and because they are in pain and lack mobility in the first weeks after discharge. The discharge from hospital places the

patient at the fulcrum of their own care. Lay care is quintessentially different from professional care because knowledge is based on 'common sense' notions of health care management. These are based on a haphazard compilation of information, which lacks a scientific basis, experience or a comparative basis to substantiate medical ideas. The diversity of family relationships, family material and social circumstances reflects the heterogeneity of society. The providers of health and social services need to be sensitive to this diversity of experience among families and single people. The organisation of primary health care therefore needs to be sensitive to the interprofessional nature of health and social problems. Today's preventive health care movement is focused on the prevention of ill health and hospitalisation and it does not extend itself to the care of patients once they have been discharged from hospital. Health planners need to take a comprehensive view of patients as they move from hospital to home.

Chapter 7

The Nature of Community Care for Acute Care Patients

A Quadrangle of Responsibility; The Hospital, Health and Social Services and the Family.

The existing community care literature has concerned itself with 'who' cares for the long term care groups. It has focused on the role of the family and the allocation of social services in the care of the elderly, the mentally and physically disabled and the handicapped. This chapter examines 'who' cares for patients discharged from acute general medical and surgical hospital wards.

In theory, patients discharged from acute care hospital wards, fall under a quadrangle of responsibility between the hospital, the family, primary health care and the social services. However, the current unstated assumption of community care policy is that convalescent patients will be cared for at home by the family. There have been few studies which have examined the needs of these patients and have been no policy directives to allocate professional after care for these patients.

This chapter examines the role and availability of the statutory services and the family. It is important to examine

the material, ideological, life cycle and gender factors which shape 'who' cares within the family. It is argued that the relative importance of these factors changes over the life cycle.

Just as the material and social relationships within the family influence 'who' cares, these factors also influence the relationships of reciprocity between neighbors. Proximity, length of residence and life cycle factors all influence if and when neighbors are available to provide assistance and what they can provide.

In contrast to the 'moral economy' of the family and informal relationships of reciprocity and altruism with neighborhood ties, professional community support is available as a result of public policy. The levels of statutory support and who it is allocated to are determined by public funds and professional guidelines. In the case of general practitioners, care is equally available to all patients, but dependent on the ability of the family to access appropriate care at the appropriate time. In contrast, social service support and community nursing is primarily allocated by professional definitions of need.

As family care is central to convalescent care, this chapter begins with an examination of the family and who cares within

the family household, and then turns to a consideration of the role and availability of 'additional' family carers. Finally, the role of Community Statutory Services and the Hospital is examined.

I. Informal Care

A The Family

The centrality of the family and, particularly marital caring, is evident from an examination of Table 26. Of those patients interviewed 34 were cared for by their spouse. Seventeen husbands cared for their convalescent wives and 15 wives cared for their husbands. Of the other family members who provide care, the children were unmarried caring for a widowed parent [the son, was caring for his father and the daughters were caring for their mothers]. In the situation of the mother caring for her grown daughter, her daughter was not yet married and she took on the caring responsibility in the early weeks.

Table 26. The Relationship of Main Carers to Convalescent Patients [Living with Permanently]

Husband	17
Wife	15
Son	1
Daughter	2
Relative	
Mother	1
Sister	1
Total	37
No Carer	7

Similarly, an elderly sister travelled to Milton Keynes to provide support and care for her sister because her husband was too elderly and ill to provide care.

If this data is considered in the light of the number of married daughters or the role of mothers or sisters who assisted in caring, the interpretation of the data becomes less clear cut [Table 27]. Distinguishing between economically active and retired patients is a fruitful way of distinguishing between the contrasting forces exerted on the family and its members. Material factors act as a powerful force on economically active couples. Among the economically active couples, providing care was difficult because employed carers had employment commitments to reorganize and they had to evaluate between competing demands on the responsibility towards work and responsibility towards their spouse. In some instances, an additional burden was placed on the family because the reorganization of work resulted in a loss of

income. Therefore the provision of after care relied on the time and availability of spouses to provide care. The combination of material and ideological forces provides an explanation of why women are carers more than men and this is illustrated in the following case studies. It was certainly the case that working husbands were helped by their children, usually married daughters. Daughters, whether they lived in the home or nearby often provided company, shopping and cleaning help for their mothers.

Table 27. The Relationship of Additional Carers to Convalescent Patients [temporary or visiting]

Son/Daughter at home	6
Married Son/Daughter & Spouse	20
Other Relatives	
Mother	1
Father	1
Mother in law	2
Uncle	1
Brother	0
Sister	1
Total	32

Table 27 confirms the centrality of children as a supplementary source of care or as sole carers. This is true of married sons and daughters who were usually grown children. They visited regularly and provided support and practical assistance.

There were noticeable differences between stage in the life

cycle and the problems which family members had in giving after care. Economically active and retired carers faced different dilemmas.

Among economically active couples, material, ideological and 'gendered' relationships are more evident. The dictates of the market place and family needs circumscribe the lives of its members. The genderisation of the male and female role within the family is reflected in the fact that many husbands provided care for their convalescing wives, although they said that they were less skilled at cooking, cleaning and shopping. A number of husbands remarked that they did not know how to budget for shopping or turn on household appliances. Thus, for many men, providing care for their wives involved acquiring new skills. In contrast, all of the wives providing care [in the economically active age group] worked part time or were full-time housewives. Their lives bridged the need to work and to care for and support family members. The nature of their employment enabled them to have greater flexibility to provide after care, although due to the part-time, semi-skilled nature of it, also meant that they lost income during any absences. Typically women's jobs were secretarial, catering or cleaning positions. Of the women providing care for their convalescing husbands four were housewives, four were employed in semi skilled, part-time occupations and one worked as a part-time shop manageress. Thus, these women could

provide considerable daily support and care. Nevertheless, the wife's income was felt to be a real contribution to the family income and the decision to miss work was not taken lightly. All the women carers had traditionally provided the household management skills. Therefore, unlike husbands, women performed the usual domestic tasks without the need to acquire new skills, and caring and domestic tasks were routines which they had worked out over many years.

In contrast, husbands caring for convalescent wives worked full-time and were the primary breadwinners. An examination of the occupational distribution of the male carers shows that five worked in skilled occupations which involved shift work, one was self employed, one was semi-retired and two were in professional occupations. [The remaining two economically active women patients had no main carer]. The male carers, in the sample, had significantly more obligations to their employment than women carers. For the five husbands employed in occupations with shift work the possibility of losing income was a genuine concern. The occupational distribution of their convalescing wives shows that; four were housewives, three were in semi-skilled occupations, one was a skilled manual worker [who later lost her job, #32], three were clerical workers and two patients were in professional occupations. Indeed, seven of the convalescing women patients had been in full time employment, and two were in part-time

employment, at the time of admission to hospital. The male carers were most likely to be able to take only one week off from work and were then dependent on additional carers to provide care. The convalescing wives of the five shift workers were each employed in part-time, semi-skilled jobs. In contrast, of the two professional/ managerially qualified women patients, one was married to professionally employed spouse and the other was single.

Thus the convalescent wives were reliant on the proximity and availability of their grown children to provide care and support. In the case of Mrs. Fera, who had no children, she requested a home help due to her mobility problems [#32].

A significant difference can therefore be seen between the women caring for convalescing husbands, compared to husbands caring for convalescing wives. The female carers were more likely to be housewives or work part time. It is however important to realize that four of the male convalescing patients had been unemployed for sometime, and had suffered ill health in the past. Their wives felt that they had to be 'housewives' because they their husbands needed continual 'looking after'. In contrast, to the part-time or full time care that wives provided, economically active male carers relied on their grown children [particularly daughters] to provide support for their convalescing wives.

Retired couples were not bound by employment and the loss of income which it could represent. The domestic division of labour, evident in the economically active couples, is not so apparent among retired couples. The gendered relationships which are evident in the employment and domestic structures during the economically active years become less pronounced with retirement. The prime difficulties for providing care for spouses, as patients become increasingly elderly was that each partner suffered some disabilities. Among retired couples the division of labour for household tasks was often shared between the partners. Typically women undertook the household tasks but couples also said that they had increasingly shared household tasks and that they each performed those tasks which their capacity or health allowed them to. Couples who had married children living within the vicinity were able to call on them for support and often help was provided without being asked. However, couples without married children were largely dependent on each other.

A few case studies will illustrate the material, the ideological and gendered nature of these family relationships and it demonstrates that fluctuations in the significance of each of these factors over the life cycle.

B. Spouses

B.1. Husbands - Retired

Mr. Jacob, [spouse of patient # 23] took a very active part in the after care of his wife. He was most solicitous , often finding that he could not do enough for her. He had a largely traditional role relationship with his wife while he had been working, but gradually after retirement with more time on his hands he had begun to participate more in household chores. Thus although his wife's sudden operation meant that he had to become more involved and learn to take on cooking and other tasks which his wife had continued to assume, he had over the years learned how to do some elementary cooking and household cleaning. As they did not have any children nearby they had to rely on themselves . Although they had helpful neighbors their neighbors were elderly, and therefore limited in how they could help.

Mr. Terance [patient # 24] took on 'looking after' his wife. He saw this primarily in terms of taking over the sole responsibility of household tasks. Previous to retirement they had a segregated division of labour. It was only since Mr. Terance had retired that they began to share household tasks. Although active and capable of taking public transportation to do the shopping and the heavier household tasks, he was not in very good health himself and took medicine for

cerebrovascular disease and was often short of breath. Their own children lived mostly in another city and found it expensive to visit. One married son lived close by but he worked and therefore could not visit easily. On those occasions that their son took his mother to a doctors appointment he had lost income. Most of their neighbors were elderly and some were unemployed so that private transportation was a problem.

B.2. Husbands -Economically Active

In the case of employed men, particularly those in the occupations with the least security and fringe benefits, they had to return to their work, but they also had a more segregated division of labour in the home and found the need to learn household tasks, at best difficult, if not occasionally irksome. Mr. Fera [spouse of patient # 32] was employed as a lorry driver, when his wife had to go into hospital for major surgery at the relatively young age of 47. As a result of this surgery Mrs. Fera was weak and had lost the partial use of her foot. Her husband took a week off from work in order to look after his wife however he was losing income as a result of this. Mr. Fera was unaccustomed to participating in household chores and found the responsibility a bit of a strain . He found tasks such as budgeting for the

weekly shopping difficult and had problems with using household appliances. They had no children on whom to call for help. Upon discharge, Mr. Fera had to help his wife negotiate the stairs in order to have a bath and to take her to the toilet. He also helped to arrange the visits she had to make to the hospital for physiotherapy treatment. Due to the fact that his employment did not offer paid holidays and he had to travel long distances which necessitated him being away from home for two or three days at a time, Mrs. Fera requested and received a home help.

Mr. Black,[spouse of # 45] an administrator, could not take time off from work to care for his wife. She was left on her own when she was discharged from hospital. Her two teenage children were at school and busy with their own lives. Due to her illness Mrs. Black had quit her job. and she was now very isolated. Although she lived in comfortable circumstances the combination of her illness, the lack of companionship, the lack of mobility, the pain and the uncertainty of the prognosis Mrs. Black desired medical follow up and advice. She felt that the transition from the total care of the hospital to the isolation of the home and the lack of community professional follow up difficult. Implicitly she was suggesting that it was the responsibility of the general practitioner to follow her up . She did not want to trouble the general practitioner herself but nevertheless felt the

need for some professional advice. This common dilemma suggests that patients sit on an uneasy fence between passive recipients and 'consumers' of health care.

Mr Hay, [spouse of # 12] a 45 year old manager, was the exception among the economically active men. He took on primary responsibility for the care of his wife. He was able to take time off from work by using his annual holiday to stay at home and he did not therefore lose income. As they had both worked full time they had a joint conjugal role relationship [Bott, E. 1957] and shared household tasks. He did not find the job of household management a problem. He was very sensitive and supportive of his wife's dietary needs and preferences. He moved a bed into the living room for her as she was unable to climb the stairs for the first few weeks after discharge. He was very worried about the suddenness with which Mrs. Hay had become ill. It resulted in them reevaluating their lives and their future.

B.3. Wives - Housewives and Retired

Women who were retired or had been housewives all their lives continued with their 'normal routines' of household tasks. The care of their husbands did not therefore represent an acquisition of new domestic skills. Among the economically active age group of women they were in some cases looking

after young or teenage children in addition to their husbands. The women were also working either part time or full time.

The situation of Mrs. Kay [wife of #43] was an exception in that she had formerly been a nurse, but it highlights the 'wifely' role she played as well as the 'nursing skills' she contributed in the care of her husband. Mr. Kay had belatedly been identified as a diabetic. Mrs. Kay, in fact, had been instrumental in obtaining the correct diagnosis. Prior to admission to hospital Mr. Kay had been visiting his G.P. for tests, however, they had not established a correct diagnosis. As result Mr. Kay had gone into a coma one evening. Fortunately, Mrs. Kay had correctly identified that the cause of the coma was diabetes and had 'ordered' the doctor to call an ambulance. Fortunately, the call had not been too late. Post discharge Mr. Kay was being cared for efficiently by his wife. She purchased needles for his daily injections, purchased and enforced the diabetic diet which he had to maintain and oversaw the strict regime of twice four hourly light snacks. She was demonstrably an active and skilled carer.

Mrs. Smith [wife of #8] was also caring for her diabetic husband. However, her understanding and interest in diabetes was less clear. She did however, prepare separate meals for herself and her husband and she attempted to monitor her

husband's eating. She did not however become so involved in his blood tests or taking the readings to monitor his sugar levels. Nor was she able to enforce his diet, and he occasionally found the temptation of sugary foods too great. Fortunately , Mr. Smith did not have to take insulin injections.

Mrs. Robbins [wife of #42] was looking after her elderly husband who was suffering from a number of health problems, of which the most painful was gout. Mrs. Robbins had considerable responsibility in his after care, both day and night. Her husband could not sleep at night because he had to use the toilet numerous times and he needed to be helped. He was also taking ten different tablets each day, which Mrs. Robbins supervised. She checked the tablets to be taken before meals, others between or after meals. Furthermore, she attempted to identify those tablets which were causing more problems than they appeared to be solving. She insisted that the doctor visit their home as she did not drive. Mrs. Robbins, herself was not in good health, and had a number of appointments with her general practitioner, and the care for her husband was making her exhausted. However, they had no children to help them.

B.4. Wives - Economically Active

Mrs. Nollins [wife of # 26] had taken on the care of her convalescing husband, who had suffered a heart attack. She had read the literature provided by the hospital on his after care and had deliberately set out to monitor his level of exercise and diet. However, as a result of Mr. Nollins also having lost his job at this time Mrs. Nollins had also taken on a full time job. In addition, they had two teenage children to care for. Clearly, Mrs. Nollins was having to shoulder a number of responsibilities. While, it was evident the household tasks and the care for two semi- independent children were automatic to her, the prospect of becoming possibly the sole breadwinner was a new role both for her and her husband. It was evident that a considerable renegotiation of roles would be necessary, if this were to occur. Furthermore, the numerous responsibilities which were being placed on her demanded her time , which made it difficult for Mrs. Nollins to care for and spend as much time with her husband as they would have liked.

Mr. Stromber [#34] had suddenly incurred a heart attack one evening and had been rushed to hospital by ambulance and had a pacemaker put in. On his return from hospital Mrs. Stromber looked after her husband. While she was obviously very concerned it manifested itself by ignoring his heart attack,

to a large extent. She was able to continue with her part time job and continued with life style habits which were detrimental to her own health and that of her husband such as smoking and inappropriate eating habits. However, when her husband had noticed an infection developing where the pace maker had been installed she was able to provide first aid skills. Jointly, she and her husband began taking regular exercise, which had not been a part of their lives previously. It was clear that the family , including, their daughter, who still lived at home, were taking time to readjust to the impact of Mr.Stromber's heart attack. Due to the fact that they had adult children near by Mrs. Stromber was able to continue with her job, as they visited while she was out.

C. Additional Carers of Convalescent Patients

Material, ideological and gender relationships also influence, to a certain extent, who additional carers are. For example, economically active males carers, in skilled jobs, were more likely to depend or rely on daughters to care for their wives. This was exemplified in the case of Mrs. Cose [#35] and Mrs. Vassar [#5]. In fact, Mrs. Cose's married daughter lost her earnings from her part time job rather than have Mr.Cose [her father] loose his earnings by taking time off work. In the case of Mrs. Vassar, her married daughter [of sixty], husband

and 18 year old son had moved into her house to provide care. At the time of moving in with Mrs. Vassar she had been working part time. However , as a result of her mother's declining health she found the demands too conflicting and resigned. Caring for Mrs. Vassar revolved around the continual needs such as cooking, giving her a bath, getting her dressed or taking her to visit her friends. It also often involved getting up during the night. Mrs. Vassar's daughter clearly felt the incursion on her life but she also clearly saw it as her duty. This was reinforced by her mother's attitude. Mrs. Vassar evidently expected her daughter's care and sacrifice.

Six other patients were cared for by a relative such as their mother, daughter, sister or son. This reflects the preponderant likelihood that women in various roles provide the care for dependent relatives. Mrs. West [#1] is an elderly lady who has been hospitalised twice in the last 8 weeks. The first time she was in hospital for a surgical operation and the second was due to some unexpected complications from the surgery. Mrs. West's sister travelled one hundred miles in order to look after her and her dependent husband. Mr. West had been physically incapable for some time and had been entirely dependent on his wife until her operation. Therefore Mrs. West's sister cared for both of them until Mrs. West was well enough to move about a bit again. Mrs. West did not have a home help or meals on wheels or a district nurse to help,

which she would have appreciated. She was quite immobile still six weeks after her discharge. Shopping was still a problem and she still could only manage to wash, rather than have a bath.

In the case of a 28 year old patient, Miss Lyle, [#25] she stayed the first three weeks convalescing with her mother after her surgery. After that she returned to live with her fiancée. Miss. Lyle's mother was widowed and retired. She had moved to Milton Keynes to be near her daughter and clearly was very concerned over her daughters health. The three week hospitalisation had been very emotionally draining for both of them and her return home entailed a lot of self care as Miss. Lyle had to learn to cope with an ileostomy. Five weeks post discharge, Miss. Lyle had learned sufficiently to cope with her ileostomy to return to work on a part time basis. Her fiancée had been unable to look after Ms. Lyle when she returned from hospital because of his job, which often took him away from home.

Mr. Gapp [#31] is the only patient in the study who was cared for by a male relative. He lived with his 30 year old son. His son cooked, cleaned and kept an eye on him. Although he clearly felt very concerned about his father while he was at work, he had no intention of giving up his job and he continued to lead a social life. This is in contrast to the

restrictions that many of the female carers imposed on or expected of themselves.

Thus, in certain situations someone other than a spouse takes on the caring role. In many instances this is another female. This is partially because of the 'availability' of women. Employed women carers, in this study worked in part time employment, as a result, a loss of their income is less damaging to the family economy.

D. Patients Living Alone

Seven patients had no main live-in carer. This was due to being single or as a result of death or divorce. These patients had to be self reliant. Of the three retired patients, one was reliant on a neighbor and an elderly sister visiting weekly; one had two married daughters who provided meals and shopping and cleaning; the other patient had no relatives nearby. Of the economically active patients, one man is a bachelor, one lady is separated from her husband and one man is divorced, although he lives with his two teenage children.

D.1. Retired living alone

Mr. Hume [#9] is a charming 83 year old man, who lives on his own in an older town of Milton Keynes. He has a number of ailments, but none of them seem to cause him particular concern. His predominant feeling is one of immense loneliness. He manages to look after himself, he does his own 'bit of shopping' , cooking and cleaning. For the rest he sits in his chair, reads a bit and listens to the radio. He has no home help or meals on wheels. He sees few people all week, as all his neighbors are elderly and don't go out and the few younger neighbors are at work all week. Only at weekends does he go to visit his daughters, who are now in their sixties. He manages to take his own medications and collect them from the health center. Indeed it proved to be important that he was attentive of the names and kinds of tablets which he took. Upon return from hospital he had to obtain a set of prescriptions. After returning home from the health center he was on the point of taking the tablets when he realized that they were not the right kind, that they were larger than the ones he had before. He then had to walk back to the health center to ask if the prescription had been filled correctly. An error had indeed been made. The amount of the tablets was filled incorrectly. Mr. Hume was very concerned that this should have happened and thought that it should be made known.

He was also upset because it had meant so many trips to the health center, which 'is quite a walk for someone of my age'.

D.2. Economically Active-living alone

Of the economically active, two were single headed households with school age children and one was recently widowed and her son had also recently left for university.

Mrs. Beaufort [#11] is an active professional woman, who had a mastectomy only months after the death of her husband. She took a very brave attitude towards this traumatic event. She was determined to resume work and as many community activities as she could. She now lived on her own in her own house, although her son returns for weekends from time to time. Her mother and brothers live nearby and are a great support to her. At the time of the six week follow up interview she was working part time again and taking driving lessons.

Mr. Drew [#39] was divorced from his wife some years ago. He had surgery, which post discharge was still causing him difficulties and he was later readmitted to hospital. Mr. Drew is unemployed and lives with his two teenage daughters. His daughters do all the house work, cooking and cleaning. Mr. Drew has successfully obtained a number of social security

benefits and while he lives in a L.A. house he has a number of 'mod cons'. While he was in hospital his daughters were looked after by some neighbors, but 'they are quite capable of looking after themselves.' He was very depressed and worried and he said that he was making an attempt to radically alter their diet. They had lived on sausages and chips but he had started to purchase brown bread and fresh fruit in an attempt to improve the family diet. While Mr. Drew had no home help or meals on wheels or nurse he had been able to obtain a large number of small benefits from the social services due to being unemployed.

Of the seven people living on their own only two discharged patients had social service help. One of these patients was Mr. Brown, a very elderly and confused gentleman and one was a younger a bachelor who had a mild heart attack.

The foregoing case studies of carers illustrate the interplay of material, ideological factors and gender which play a changing role over the life cycle. During the economically active years these forces play a central role in determining who within the nuclear family cares. However after retirement the material factors play a diminishing role. Gender remains important as female relatives, particularly daughters, predominate as additional carers. The case studies show that

in the economically active age group employment and the loss of income are instrumental in influencing who cares for the convalescing patient. Reflecting on the patients and their carers it is striking the active nursing skills that women, at whatever age, brought to their role as carer. Husbands appeared to feel somewhat at a loss in contrast. On the whole, husbands made an attempt to take on the 'role of wife' and fulfilled household tasks and provided care and companionship to their wives. However, many expressed a feeling of ineptitude. The interviews suggest therefore a partial critique of Gilligan's argument [Gilligan,C.,1982] that women through the process of socialization acquire a moral language which is central to one of nurturing and caring. The evidence of greater segregation of role relationships and the 'genderisation' of caring is most evident among economically active couples, particularly in those where the husband had few fringe benefits or flexibility in working hours. Her argument concentrates on the genderisation of caring and ignores the structural influences which affect caring roles. This is evident among retired couples the genderisation of roles was less pronounced as the economic structure becomes a reduced influence in their lives. To distinguish the social world of women as being more characteristic of love and concern and inimical to the needs of the capitalist economy may more aptly describe the child rearing stage of the life cycle. Women and men take on separate division of labour in

order to become more efficient in their tasks. Certainly in the crisis situation of hospitalization and ill health the functions normally associated with women were taken by most husbands, albeit with less efficiency and competence.

The delicate balance of caring relationships was particularly highlighted in situations of inter-generational caring rather than intra-generational caring. This was often expressed by patients in terms of gratitude for the care which they received. Carers often cited the obligation which they felt to provide care due to help which they received in the past. Nevertheless both patient and carer were aware of the foregone opportunities that the provision of care represented. The provision of care placed restrictions on the social life and in some cases the possibility of employment for carers. This of course depended on the length of the convalescence. In some cases the period of recovery is anticipated to be of a fixed duration ,[such as by Miss Lyle's #25] mother] however in the situation of Mrs. Vassar [#5] and Mr. Gapp [31] it became a long term commitment for their daughter and son.

E. Costs to the Family

E.1. Direct Economic Costs

Economically active patients and their carers were vulnerable

to the loss of income and of their employment. This was particularly the case for those in least skilled occupations. Of the twenty five patients in the economically active age group three patients lost their employment and four patients lost income as a result of their illness [Table 28]. Of the four patients it was those patients in the least skilled jobs who were more likely to suffer a reduction in income. Similarly carers in the least skilled occupations were more likely to loose income by providing convalescent care. Six economically active spouses lost income in order to provide the after care. In contrast, retired patients were not exposed to a loss of income. However, retired pensioners without occupational retirement pensions lived a very restricted lifestyle. They had access to fewer resources, such as a car, to enable them to visit the doctor, friends or to pursue interests outside the home.

Table 28. Direct Costs of Ill Health [5 to 6 weeks after discharge]

Loss of Income

Patient	Main Carer
4	6

Loss of Employment

Patient
3

Return to work

P/T or F/T
6 0

Unemployed

4

[Total of 25 patients in the economically active age group]

Thus for the economically active, particularly, the direct cost were very real and immediate. Patient and carers terms of employment dramatically shape the kinds of decision the family has to make in terms of competing demands between the necessity to provide an income for the family and the responsibility to provide care for family members. It is a competing decision between labour for 'exchange value and labour of love for 'use value'.

The direct costs to the family not only involved potential or actual loss of income but also additional 'hotel' costs in terms of the provision of heating and food. An additional cost to the economically active family is payment for prescriptions. In some instances these costs were substantial. Thus a less obvious saving for the national health service of discharging patients earlier is that there is a saving on hospital prescription expenditures. However, for long term medications patients were given financial assistance. The direct costs for the retired were not associated with increased 'hotel ' expenses because they had been at home before their hospitalization, nor did they have to pay for prescriptions, which would otherwise have represented a major burden on their limited resources . Patients who were offered home help services or meals on wheels were expected to pay for

these services in relation to their savings. This was felt, by many of these patients to penalize those who had worked hard all their lives to save money for retirement.

E.2. Indirect Costs

Chapter 2 reviewed the literature on the emotional and social costs of caring for the family. It is evident in this study that there were many similar problems . Patients and their carers experienced emotional stress, social isolation and anxiety. This was evident in their daily lives, which were dominated by the minutia of changes in emotional states and perceived or imagined medical states.

One of the central problems was the anxiety created by such a sudden and acute episode of ill health and the feelings of inadequacy in coping with it. In addition , anxiety over the eventual outcome of the patient was a dominating preoccupation among the patients and their families alike. Patients and their families all expressed the wish for medical follow up to help them develop strategies for coping and to provide reassurance.

F. The Role of Friends and Neighbours

The community care policy , as it was originally conceived, envisaged a central role in the care of discharged patients to be played by 'friends and neighbors'. The literature review suggested that support from these groups of people was limited. In this study, a similar result was found. The level and type of support varied according to the length of residence, the stage in the life cycle and the social sphere in which the patients lived. It was clear that the nature of neighboring activity is normatively prescribed. This affected the degree of involvement and the nature of the help requested. Neighbors were primarily asked for help in an emergency situation or for specific limited tasks, such as transportation or the use of the telephone.

The district health authority has expressed particular concern over the likelihood of the availability of friends and neighbors to provide aid and assistance to people discharged into the community. The interviews with the convalescent patients were concerned with characterising levels of 'community' support by friends and neighbors in Milton Keynes. This has been of particular interest in Milton Keynes because of its relatively 'new' population.

A crude indicator of social networks and the availability of

friends and neighbours is the length of residence. Table 22 in Chapter 5 shows the length of residence of the study sample. It reflected a concentration of the elderly 'locals' on the perimeter of Milton Keynes new city and a 'new' population in the more recently developed areas. The interviews however, would suggest a more complicated relationship between the support by 'friends and neighbors' than a simple linear relationship with length of residence. Indeed the interviews suggested a combination of factors were influential in determining levels of support. These were a combination of factors specifically, the stage in the life cycle, sex, length of residence and levels of perceived reciprocity. Thus a more accurate view would be based on social spheres based on levels of ability to reciprocate which are dependent on material resources, locality, and on levels of social involvement.

While patients who had lived locally all their lives need to be differentiated between those who are newcomers it is also necessary to consider the stage in the life cycle. Of the three elderly gentleman, who lived locally all their lives, one could not depend for assistance on his elderly neighbors. The types of assistance which his neighbors could provide was minimal. As Mr. Hume [#9] who lived on his own, said 'Mr. Roy lives two doors away but he's as deaf as a post, and the majority of the people around here can't get out to walk.' He

clearly felt very isolated and would not be able to have any assistance from his neighbors.

In contrast Mr. Brown, [#6] who also lived on his own , was highly dependent on a younger neighbor. His neighbor was an exception. Mr. Brown's neighbor looked in almost daily and checked to see if he had eaten his meals and that he was alright. However, the neighbor expressed the opinion that he was being taken advantage of by the social service department. He felt that it had become his responsibility to check that Mr. Brown was eating the food provided by meals on wheels and had only recently had to call the police to break into the house because Mr. Brown had fallen and was unable to get up.

In the case of Mrs. Terance [#24], an elderly lady, who moved recently to a Milton Keynes estate with her husband, lived in a different set of constraints. She had become friendly with one younger couple on the estate. The younger couple, although willing to help, were living on unemployment benefit and could not afford to provide much practical assistance. Mrs. Terance had occasionally received help from them in the form of transportation but this couple could no longer afford to run their car and Mrs. Terance felt reluctant to ask help from them because of their financial hardship.

Among the economically active couples Mr. Nollins [#26] had moved into a new housing estate in Milton Keynes 4 years ago.

As both he and his wife worked, they had only gradually come to know their neighbors. The neighbors whom they had become acquainted with all worked, so during the day Mr. Nollins was left on his own during the hours his wife worked.

In contrast, Mrs. Hay [#12] who has lived locally all her life, and until her hospitalisation has led a busy life working and being involved in community activities, had a number of visitors. Visitors from her work colleagues, church friends and other callers who were willing and able to provide assistance. Her visitors kept her company while her husband was at work and as she gradually recovered they took her out for short trips. Relatives living nearby also called in to see her and did some shopping for her.

From these case studies it is possible to see the significance of the stage in the life cycle, the length of residence and the social sphere in which patients live, to the level of neighboring activity. Stage in the life cycle is an important indication of the likelihood of neighboring activity. The very elderly people were more likely to be isolated because their friends were either ill or had died. Indeed their own children were no longer young and may have started to experience some ill health. Furthermore , patients who were very elderly no longer had a car and levels of community involvement declined. In contrast, the economically active patient are isolated

because their friends and neighbors were at work themselves or busy with their social commitments. Although patients in the economically active age group, who were unemployed, also were isolated, particularly if they were new to the area.

Comparing the lives of patients who are newly resident to those born and bred locally exhibited differences in reciprocity between neighbors. Assistance was more likely to be offered when the patient had been locally resident for a long period of time. Established relationships of reciprocity could continue. In contrast , patients who had only recently moved to the area were particularly isolated. A history of reciprocity had not been established. Little help was offered and patients were reluctant to impose on neighbors. It was clear however that this stark distinction was not sufficient to explain 'neighboring'.

The particular social spheres, in which people live also influence the level and type of help from neighbors. The social spheres, in the community, are grounded in particular localities with different levels of resources and different capacities. Elderly patients living in a community among other elderly people have contact primarily with other elderly, frail people, living on restricted incomes. Some housing estates are comprised of many people living on restricted incomes and therefore the types of support or assistance which

neighbours could provide were limited. For example, a patient living in a low income area, could not think of a person who had a car which was working. In contrast, families in economically active age groups living in areas where the majority of families work are isolated as patients. As one patient said ' the housing estate is empty during the day'. Thus despite the higher standard of living and the availability of automobiles the neighbors of patients often do not have time to spend with a convalescing neighbor. Thus the concept of neighbourliness is not directly related to deprivation or affluence but tied to a complex of social and economic factors.

II. Statutory Provision: Social Services and Health Professionals

Statutory care, as opposed to family lay care, is vital for the maintenance of patient health in the community. The interviews suggested that patients and their carers were primarily concerned with contacting the medical profession, particularly maintaining contact with the hospital consultant or their general practitioner in the first weeks after discharge. The use of the social services was rarely mentioned. It suggests that families have different

orientation to and expectations of the respective professional services. This also reflects the nature of the provision of the respective services as well as the immediate needs which patients have when they are discharged from hospital. The social services offer their services only if 'clients qualify', whereas the general practitioner is available as a 'right.' Contact with the general practitioner is self selective and dependent on the patient and their carer to identify appropriate occasions to utilize the service. Community nursing services are largely allocated on medically defined need and not patients definition of need.

A. Health Professionals

Table 29 indicates the extent of medical contact for the study sample. Contact with health care professionals could be with hospital consultants, general practitioners, nurses, occupational or physiotherapists. Follow-up appointments with consultants are initiated by the consultants at the hospital and therefore 'rationed' according to medically perceived needs. In contrast, the general practitioners rarely initiated contact with patients discharged from hospital. The result is therefore a system in primary health care that medical attention is dependent on a self selective procedure, dependent on the patient and their carer to identify

appropriate needs and times to contact their doctor. It is dependent on patients taking a 'consumer approach' to their health care.

The majority of patients had follow-up outpatient consultant appointments within the first six weeks after discharge. It was viewed by patients as a 'progress report ' which they looked forward to, to confirm the adequacy of the care which they had provided. However the expectations of the visit often met with disappointment because they sought an individual reassurance from medical expert, the consultant. These interviews highlighted the differing medical and lay perspectives. The routinisation of the medical encounter was both reassuring and impersonal for patients. It confirmed that the 'illness' was not experienced solely by the patient and this had the effect of 'normalizing' the experience. However, patients experiencing their first major illness, were seeking individual explanations for their current 'deviant 'health status.

The literature on the utilisation of general practitioners indicates the complexity in the behavior of patients. In this study few patients had seen the general practitioner more than three times in the first five to six weeks post discharge and some patients had not seen their G.P. at all.

Table 29. Patient Contact with Health Professionals

Age	Consultant Outpatient		General Practitioner		Nurse		Physio- therapist	
	Patient Init.	Hosp Init.	Patient Init.	G.P. Init.	Patient Init.	Hosp Init.	Patient Init.	Hosp Init.
Retired [20 patients]		12	11	2	1	7		
Economically Active [25 patients]		16	19	2		1		3

A study by Dr. Miles [Miles,G., 1983] suggested that people were more likely to contact their general practitioner if they lived in the new city estates than if they were 'established' in the area and lived in the older parts of Milton Keynes. The study sought to identify the relationship between the availability of 'friends and neighbors' as inhibitors of the use of health services. In this study the evidence suggests that almost all the patients contacted their general practitioner once they were discharged. This was often 'legitimated' by the necessity to give the 'discharge note' to the general practitioner and to obtain a another prescription for tablets.

Some patients indicated that they were inhibited to visit their doctor due to transportation constraints. Families who

did not have a car found visiting the surgery was often prohibitive due to pain, lack of mobility and expense. This was particularly true of the 'underprivileged areas' of Milton Keynes where patients lived in social spheres, where a combination of unemployment and an elderly population had little access to cars. The general practitioners in these areas , given the level of potential demand could not afford the time to make house calls. This suggests that an inverse care law may exist in these 'pockets' of Milton Keynes.

The role of the general practitioner is also to act as gatekeepers of both other medical professionals, such as nurses and they can also refer patients to the social services for meals on wheels or home help support. A central part of the community health care policy and the policy of earlier discharge relies on the availability of community nurses to provide, aid and assist in convalescent care. The majority of patients, however, did not see a community nurse. Community nurses were assigned to patients who had open surgical wounds or were learning how to monitor blood sugar levels in the case of diabetes. Given the level of demand for medical expertise by patients and their carers, the lack of community nurses in this study, indicates an area of services which are under provided.

A total of nine patients [Table 30] had a district nurse visit

them in their home. Six of these patients were retired. The three patients who were in the economically active age groups had severe heart problems or major surgery and were no longer employed. They were among the most severely ill. The patients therefore who received a district nurse all had a clinical 'medical' reason for the visit. Nevertheless it was significantly more likely that a patient would receive a nurse if they were in the retirement age group. It is also worth noting that more men had a visit from a district nurse than women. There were however, women in the sample who had major surgery but who did not receive a visit from a district nurse, in both the retirement and the economically active age group. Certainly the patients in the economically active age group who received a visit from a nurse were seriously ill. In short, nursing services were restricted to a minority of patients, despite patients expressed wishes. As an elderly gentleman said [#9] " I think that the services have almost faded out now."

Table 30. District Nurse Visits:

Age		Hospital Wards	
		Surgery	General Medicine
Retired			
Males	5	2	3
Females	1	1	0
Total	6	3	3
Economically Active			
Males	2	1	1
Females	1	1	0
Total	3	2	1
Total Patients	9	5	4

Patients felt that it was often difficult to identify when it was appropriate to contact the doctor. As Mr. Maple said [22] said ; "At the hospital you have all the attention of nurses, but while you are at home you wonder if a complaint justifies calling out the doctor". Patients expressed wishes to visit the doctor or to have a nurse visit them, many more times than the contact that they already had. Patients wished to have not only medical advice but they sought reassurance to normalise their experience. The hospital to a certain extent provided this reassurance because of the continual availability of doctors and nurses and the realization that

there were other people encountering similar problems as themselves. Secondly, patients felt that they were being 'looked after' ; that the responsibility for their health was either 'given to the doctors or at least shared with them.'

Table 29 shows that after care in community is largely patient initiated . The major source of medical initiated contact was through the consultant follow up appointments. In total 28 patients had a follow up appointment with a consultant. They constituted the main professional group to initiate contact with patients. Hospital based community nurses were the second major group to organise follow up patient care. In total nine patients were visited by a community nurse. In fact, as the table shows there were significantly more community nurses organised through the hospital than through G.P. practices for these patients. In contrast to the hospital organised services general practitioners played a small role in initiating contact with patients once they had been discharged from hospital. Only four patients were visited by their general practitioner as a result of the discharge letter. Contact with general practitioners was therefore in almost all visits initiated by the patient or their main carer.

Table 29 also shows that the role of other related health professionals was minimal in the after care of convalescent patients. Despite the increased pressure to discharge patients

earlier to their homes, the lack of occupational therapists to make home assessments was evident. Despite the important role of the occupational therapist, only one patient had an assessment by an occupational therapist before returning home. She [#32] had either temporarily or permanently lost the use of her foot. Nevertheless a number of patients would have benefited from a home assessment, as there were other patients who were also largely immobile in their first weeks home and had no carer during the day. A useful indication of those who would have benefited from this are those who live on their own, or patients whose main carers were at work all day and suffer while convalescing patients have problems with mobility.

Despite the problems in mobility [Table 25] only three patients had care from a physiotherapist post discharge. These patients were all in the economically active age group and had a surgical operation.

B. Social Service Provision

Due to the long term nature of the ill health and disability experienced by the priority groups the literature has focused on the needs of these groups in terms of their relationship to the provision of the social services. Indeed social service policies are predominantly orientated towards these

groups. "Eligibility" for social service support, such as home helps, is established, in principal, according to physical criterion such as 'housebound, 'bedfast' or 'mobility'. In practice, 'eligibility' for home help provision is orientated towards the elderly and to the physically disabled. This excluded many patients for whom help may have been appreciated.

Despite the thrust in policy towards care for the 'priority' groups, the Audit Commission demonstrated the inadequate nature of statutory support. The discharge of these individuals from hospitals and long stay institutions has occurred at a more rapid pace than the provision of statutory support. Thus, even the statutory support for the priority groups is limited. In Milton Keynes the resources of Home Help support are already overstretched. In this study, few people had a Home Help, regardless of age. Among those who did it was either because they had specifically requested it, or, as in the case of Mr. Brown, [#6] he was not really capable of caring for himself.

Out of the total of forty six patients discharged from the general medical and surgical wards only four patients had home help. Two of these patients were over seventy years of age, and one was recovering from the removal of a brain tumour and a bachelor who lived on his own and was recovering from a

heart attack. The organization of hospital discharges for elderly patients [those over seventy years of age] went through the Community Liaison Officer. Thus they were more likely to receive support from social services as a result of this assessment. Some elderly patients refused the home help services either because they felt that " we will manage while we can", or they thought that by having 'home help or meals on wheels' it implied 'being elderly'.

The small number of patients who received social service support makes it difficult to generalise as to how Home Help is allocated. In the sample there were both patients who would have appreciated it as well as patients who wanted to be independent as long as possible. Of all the patients only one, Mr. Brown [#6], received Meals on Wheels.

It was, however, also the case that one or two patients had used the social service department and had become acquainted with their entitlement and had gained access to benefits which other patients did not know about or refused to have.

Social services are also responsible for distributing aids for the home. Of the forty-five patients only two patients had been provided with aids by the social services. These included a ramp for a patient's wheel chair. He had also purchased aids for himself over the years. These two patients had been in

hospital a number of times and they are the only examples in the study of patients receiving aids. One patient had however been promised a bath rail, but was still waiting for it six weeks after discharge and until that time would not be able to have a bath.

Table 24 considered the well-being of patients. In any discussion of statutory provision it must be considered in relation to need. It is clear that the majority of patients of all ages experienced immobility and depression after surgery or a heart attack. The isolation that many of the patients experienced was typical for both 'elderly patients and for patients with spouses who were economically active and who had no alternative carer. The interviews tell their own story of the difficulties which patients are still experiencing six weeks after discharge. They are still relying on their families to provide social, emotional and practical help. It is clear that General Practitioners are the only readily available access patients have for professional help or access to the social services. Nursing and social service help is allocated to or offered to patients on 'medical' criterion and there evidently was a gap between patients defined need and professionally defined need.

To the extent that home help is offered or available, it

focuses on physical impairment. The limited availability of Home Helps meant that patients both in the economically and retired age groups who had limited mobility and did not receive a home help. Nevertheless, it could be argued that home helps could also be usefully allocated to patients experiencing isolation and depression. The notion embedded in the community care policy that patients will 'return to the warmth and security of their homes,' is only partially true. Patients or their carers did not have either sufficient experience or medical knowledge to be able to make a reasonable diagnosis or prognosis of the situation and this contributed to feelings of depression and stress within the family.

C. Volunteers

The Community Care policy stated and assumed that community volunteer services would play a significant part in the care of the priority groups in the community. Milton Keynes has experienced a growth in the volunteer sector in recent years. The indications are that despite the growth in the service it is not keeping up with demand even for the priority groups. For example, the Milton Keynes Mental Health Association can get almost no funds for home befriending for clinics and day centers. In this study, none of the patients interviewed had

received help from a volunteer organisation.

III. Conclusion

"Between the idea, And the reality, Between the notion and the act, Falls the shadow {T. S. Eliot , The Hollow Men, I}

To paraphrase T.S. Eliot between the idea, and the reality of community care falls the shadow. The idea of community care has tremendous emotional appeal but it obscures the realities of the nature of the community, both as a source of care and as a demand on community professional services, it avoids the concept of patient needs and it ignores the problems of establishing communication networks between the family and statutory services. Furthermore, it assumes idealistic notions of the level of neighborly support. Indeed, in the shadow of current health care policy is the crisis of care for those patients who are being discharged from hospitals into the community. The current unstated assumption of hospital discharge policies is that acute convalescent patients will be cared for in the community, dependent on a network of responsibility between the hospital, the primary health care team , social services and the family. This has been assumed with little or no follow up of their after care in the

community, levels of need and social, and medical problems post discharge.

The analysis of the interviews demonstrates a quadrangle of responsibility with the family at the center of providing care. The role of the hospital, primary health care and social services support is temporary and sporadic and limited to the tip of the iceberg of need. The transition from hospital care to community care is in reality a shift towards the role and responsibility of the family to provide health care. Cultural and normative expectations are such that spouses provide care for each other. Although marriage vows are a powerful force in determining caring responsibility, material, ideological and gender also play a fundamental role in determining caring roles. These forces exert powerful external and internal controls over caring behavior. Material forces are particularly dominating in selecting a carer among people in the economically active age group. Husbands were not always able to care for their convalescing wives and married daughters often became the main carer, if they lived nearby. In contrast, in retirement the role of material forces were not so apparent, and there was a decline in the genderisation of household tasks, which was more apparent in the economically active age group. However, among the retired or single headed households the availability of other relatives made a significant difference to the quality of their lives.

Daughters predominantly took on the care of their elderly parents and the evidence suggests that sisters and brothers are less likely to provide care for their siblings. Pressures on families to be geographically mobile means that the reality of being able to provide care for brothers, sisters and parents is difficult if not impossible. Furthermore, the mobility of the population has resulted in 'communities' with limited family and social networks. The availability of 'friends and neighbors' on whom so much of the community care policy rests is lacking in reality for many of those new to the area. Although, some patients were born and bred locally and had more extensive kin networks, the degree of support received from friends and neighbors in the new city was circumscribed more by the social and geographical spheres in which patients lived. Factors such as age, mobility, length of residence employment, income all influenced both levels of support required as well as support which could be offered. The very elderly, the newcomers and the unemployed were the most isolated. Unwritten rules of reciprocity furthermore dictated 'what could be asked' of neighbors and this particularly affected the least mobile, the least affluent and those with the smallest social networks.

In the light of patients feelings of depression, pain, lack of mobility and anxiety over their prognosis the transition from hospital to home was an abrupt change. The desire for and

the dependency on statutory services in the community supports the argument that the current situation is hostile to community care. Economic and social policy combined with professional enclaves have militated against the implementation of community care. The reality of statutory community provision is that the family has to act as a broker negotiating its own community professional expertise. Patients must increasingly become active and knowledgeable 'consumers' of medical care. Yet, likelihood of a patient contact the doctor is contingent upon lay concepts of health care as well as material and practical arrangements. The allocation of statutory support services, such as district nurses goes to a few of the most needy. The service leans towards the care of the elderly and towards the care of surgical or severe medical patients and it therefore overlooks many patients who were very anxious for follow up in the community, particularly in the first week post discharge. The six week follow up with the consultants, which approximately one half of the patients were given, was much appreciated, but a consultation with a health professional would have been useful for many patients in the interim.

The constant public debates about expenditure on health and social services are in sharp contrast to the privatised costs of caring for the family. It is therefore important that the material, ideological and gender relationships are understood

within the family and within the community. Pressure on economically active families to meet their commitments to work and maintain levels of income were more difficult for those in the least skilled occupations. The least well off are not only more likely to incur ill health but they are also ill health but they are also more likely to experience greater hardship as a result of it. Furthermore, while women occupy the least well paid jobs in the economy there is a greater likelihood that they will loose their job due to ill health or resign from their job to care for others. Thus, families and women , in particular, are likely to bear the costs of dependency.

The support from the 'community' varied with their length of residence, their age, their geographical and social milieux. For both the elderly and couples on low incomes, not only were less likely to have a car, but they were also more likely to live in a social or geographical milieux where access to a car was difficult. This was due to two reasons ; one , they lived in an area which was predominantly composed of people on low incomes or because their social relationships were peer bound. The elderly were more likely to know other elderly people , who also had no access to cars, who were physically frail and were on low incomes. In contrast, economically active newcomers often lived in comfortable housing estates which were empty during the day.

Thus , both geographical localities and social spheres acted as major determinants of resources available. This emphasizes the need for community care policies to tailor their services to specific localities.

The interviews confirm that despite the attempts of the NHS to provide care on the basis of need that there are unmet needs among those who have recently been discharged from hospital and that those with less economic resources faced competing demands between the provision of after care and the need to earn income. If this is applied on a national scale and taking into account the epidemiological distribution of ill health and the demographic characteristics of an aging population, then it has significant implications for the allocation of community resources.

Indeed the statistics as well as the personal biographies would point to the inherent problem of need and the distribution of resources. There is a tendency embodied within the structural forces in society to lean towards an inverse care law.

Chapter 8

Professional and Lay Health Care

" At the hospital you have all the attention of nurses. While you are at home you wonder if a complaint justifies calling out the doctor. " [patient]

The House of Commons Social Services Committee, chaired by Renee Short recommended that nobody should be discharged from hospital without a practical individual care plan being devised by all concerned. Discharge planning would facilitate the coordination of the respective professional services to tailor the needs of patients in relation to their domestic resources. [Clode,D., March 1985]

The Community care policy is not only shaping the relationship between the state, social services provision and the family but it is also shaping the relationship between the state, the medical profession and the family. The policy of de-institutionalising patients from institutions and discharging patients earlier from general hospitals has profound implications for both primary health care services, social

services and for the family. This necessarily involves a clear examination of four interrelated institutions; the hospital, primary health care, social services and the family. It strikes at the heart of the relationship between professional and lay care, between individual responsibility and society's responsibility. It is clear that responsibility for care of patients is shared between the hospital, the primary health services and the social services in conjunction with the family. However, this interfaces different organisational structures, different areas of knowledge, expertise, authority, rights and obligations. A high degree of collaboration and coordination of services is necessary for the community care policy to be effective.

Fundamentally, the nature of hospital care and primary health care is different. The differences are a result of the structure and organisation of these services. The capital concentration of the hospital affects the nature and type of relationships with the 'objects' of the service, the patients. Similarly, the relative dispersal of community health centers means that they are geographically closer and more identifiable to patients. However, the total responsibility for care provided by the hospital is not provided in the community. Patients are required to become active participants in their own health care. They must be knowledgeable, seek advice when it is appropriate, evaluate advice, identify and

coordinate the use of relevant services. The relative dispersal of professionals in the community makes communication more problematic between the hospital and the general practitioner as well as between professional community workers. It becomes therefore more imperative that patients are adequately informed and knowledgeable about their health, convalescent care and health promotion.

I. Institutional Care

The district hospital remains the center of capital resources. It contains a concentration of capital, both in terms of knowledge, skills and experience as well as capital equipment and expenditure. It is the focus of resources for a single goal, that of health care. With that objective, services are organised with an ideal of achieving a high standard of care within cost effective budgets. In order to achieve these goals the hospital, like other large organisations, establishes a hierarchical division of labour with differing responsibilities, power and authority. The institutional goals dictate the organisation of time and tasks. The specialisation of roles creates a reliance on and an interdependence between the professional workers. The interdependence of specialised personnel entails that the work schedules are sequential. Hospital management seeks to co-ordinate services and to achieve organisational efficiency. For example, it schedules

the daily cleaning meals, ward rounds and operations in a routine to maximise doctor time and the availability of the majority of the patients. The efficient use of qualified personnel and equipment are routinized in a way which will facilitate a continual flow of care services.

The organisation and administration of the hospital necessarily have inherent implications for the 'objects', of the service, the patients. It was precisely the organisational aspects of institutional care which created the debate on the benefits of institutional care by Goffman and Illich in the 1970's. The hospital is a prime example of some of the characteristics aptly described by Goffman in his concept of the total institution. NHS demands for greater efficiency and a cost effective use of resources entails that relationships with patients are based on the overall organisational goal of the hospital. Relationships between the health professionals and the patients are specific and one dimensional. As a consequence, the relationships between the health professionals and patients are typically impersonal and secondary. Due to the concentration of medical expertise and equipment in the hospital all aspects of a patient's life are conducted in the same place under a single authority and each patient's daily activities are carried on in the immediate company of a 'batch' of others. Hospital routines entail that all the patients are required to do the same thing together

at the same time. For the patients and the staff, each phase of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next. The whole sequence of activities being imposed by a system of explicit formal rulings and a body of officials. The overall functioning of the hospital is determined by the hierarchical relationships within the hospital and the degrees of authority which each position conveys. Finally, the various enforced activities are brought together into a single rational plan designed to fulfill the official aims of the hospital.

It was this typology which precipitated the critique of hospitals and other total institutions in the 1960's and 1970's. It was argued that the anonymity, batch living and impersonality which total institutions came to represent were not conducive to health, in the broadest sense of the word. However, these very same characteristics, so aptly identified by Goffman, can also illustrate the strengths of institutional care. The hospital not only provides 24 hour care, by skilled, experienced personnel, in one site, but it also offers medical equipment which has life saving potential. The large, specialised staff, who co-ordinate responsibilities, share the care for all the patients and they are available twenty-four hours per day. Therefore the burden of caring does not fall on an individual but on a number of highly trained individuals. The secondary nature of these relationships which

have no emotional content or bonding can be conducive to different types of discussions about lifestyle, health care and the patient's future. The organisational characteristics of the hospital therefore have specific implications for the experience for patients.

This overview of the characteristics of the hospital needs to be compared to the structure and organisation of care in the community. The structure and organisation of primary health care, as opposed to social services, is particularly important to acute care patients.

II. Community Statutory Care; Health and Social Services

Definitions of community care have uniformly implied two aspects of community care. One, is that community care is non-institutional care, and secondly, that it is provided by formal, quasi-formal and voluntary helpers. The organisation and delivery of community care is fundamentally different from institutional care. The two central statutory services in the community are the general practitioners, increasingly based in health centers and the social services. The health centers enable doctors to share common facilities. They also provide the organisational structure which should be conducive for the exchange of ideas and the possibility for the reduction of the workload of individual general practitioners. Indeed, the

establishment of health centers was viewed as an attempt to share care jointly between health center general practitioners and attached community nurses. This it was thought would ease the burden on individual general practitioners and also provide easier access for patients.

The differences in the structure and organisation of health and social services is reflected in the use of and access to the respective services. Social services provision is based more on professional identification of need and eligibility. Formal or informal criteria establish, for example, who is eligible for home help services or meals on wheels. In contrast, primary health care is care which is self identified, and 'taken to' the general practitioner. The general practitioner may legitimize the complaint or not, but a patient can determine his own criterion to visit the G.P.. The general practitioner, can also be instrumental in facilitating social service assistance. He can act as a gate keeper to other professional services.

Access to the general practitioner is, in theory, equal for all patients. A patient's general practitioner can be contacted for at least eight hours per day, and a general practitioner is always on call. In practice, the health center approach, although improving the accessibility to general practitioners, it has also resulted in a decline of house

calls and personal general practitioners. Indeed, the increased pressure on primary care givers in recent years to take on patients discharged from long stay institutions and 'early discharge' patients would suggest that the availability of general practitioners to make personal house calls would be less precisely when they are needed more.

In contrast, the organisation of social service provision, is provided through the Local Authority. Individuals or 'clients' must fulfill rules of 'eligibility' and they generally do not contact the social services directly themselves. The home help service is usually given on the recommendation the general practitioner or a social worker. This necessarily means that the social services have a problem in targeting their clients and in identifying where their services are needed most. Thus there is a problem of identifying the 'incidence ' of need. [Baldock,J., 1986] . They have the additional difficulty of identifying levels of appropriate scope of their services. Some clients are helped sporadically, while others have no support and still other clients have a great deal of support. Thus there is considerable variability of provision in relation to need. For example, meals on wheels services may be organised for some days of the week and not others. Partial and unpredictable services make it difficult to have continuity and seek additional help from informal carers. Furthermore, as the

service is organised according to rules of who qualifies for assistance, it necessarily means that some people are excluded. Thus, in the case of earlier discharge schemes younger age groups are not included in the criterion for home help. Beale, [Beale, G., 1978] found that professional care in the community is more likely to be organised within the segregated professional goals of each profession. Indeed the study of health centers found that despite the concentration of multiple services in health centers there is little interaction between the professions. This implies not only a potential concentration of services on a few individuals , the neglect of others and a greater reliance on the family to identify and coordinate the use of appropriate services.

Despite the ideal of community services and the development of health centers, professional work schedules become intra-professional rather than inter-professional, as each professional group dictates its own goals and responsibilities. Due to the lack of visibility and interdependence of the respective professional's work , a greater reliance is placed on the family to identify appropriate services and to co ordinate them. For example, health visitors and social workers each do a proportion of home visiting resulting in the possibility that the coordination of services ultimately resides with the family. It therefore becomes more imperative that patients and their

families become 'active participants ' in their own evaluation, identification and administration of health care. In this study, this was exemplified by the fact that contact between the hospital based consultants and doctors was primarily through the discharge letter which patients took to their G.P. Thus , the notification of hospital discharge lies primarily with the patient and future contact with the general practitioner is dependent on patient initiative. Direct contact between hospital and community doctors is limited.

The coordination of health and social service professionals becomes potentially more problematic because they do not come under a single financial or administrative umbrella. The current policy of 'bridging funds' indicates a recognition of a basic need to co-ordinate services. [Clode,D., March 4, 1985] However, the data on funding indicates only a small growth for bridging funding although, in the face of rapidly increasing numbers of 'patients' in the community , needs will outstrip resources. Indeed " the national picture of social service provision growing fractionally and yet just about keeping up with need is a generalisation subject to so much internal variation as to make it an image that is untrue as much as it is true." [Baldock, J.,1986, p.174]

In the case of the Oxford Regional Health Authority ,as Chapter 4 has indicated, there is a shortage of nurses, at the

same time as an expansion of potential demand. The new hospital in Milton Keynes and the growing population of Milton Keynes are likely to mean that patient needs far exceeds supply of community health professionals.

A consideration of the characteristics of professional care illustrates the common nature of hospital and community care.

III. Professional Care- The Unification of Statutory Provision

The fundamental characteristics which are shared by both hospital consultants and general practitioners is their common professional role based on shared knowledge, authority, experience and ethical codes of conduct. Freidson [Freidson, E., 1970] has identified central features of a profession, which together distinguish it from both other occupations and lay knowledge. ' A profession is a group of people who perform a set of activities which provide them with the major source of their subsistence, it is a group of people who perform the same activity and develop common methods; it has a prolonged specialised training with a service orientation, which has a position of legitimate control over its work; have special knowledge and expertise which is

different from laymen' [Freidson, E. 1970, p.71].

In addition, medical training inculcates a common code of ethics which make it a cohesive, self identified group. Together the medical training , the code of ethics and the idea of providing a service for the well being of others creates a special status for doctors, which is legitimized by lay clientel and embodied in the formal practice of registering. These central features which distinguish a profession are a part of the training which doctors and consultants receive. The prolonged period of training teaches etiological notions of disease , empirical knowledge and techniques by which those states of disease may be arrested, cured, repaired, removed or improved. In particular it creates concepts of health and illness which have their own coherent explanations of causes, responsibility and techniques for intervention. Furthermore, the designation of certain human states as 'diseases,' with greater or lesser extent of 'culpability' are central features of current medical training. These diseases are increasingly linked with individual life style behavior.

Medical knowledge, based as it is on a prolonged specialised training, both influences lay concepts of health and it also creates feelings of dependence and inadequacy among patients and their families to cope . An examination of the

characteristics of the family and the nature of lay health care illustrates that it is fundamentally different from professional care.

IV. Lay Health Care and The Family

In contrast to the relative homogeneity of the hospital environment, the community is composed of families each with its own unique experiences, problems and resources. The heterogeneity of communities becomes a central problem for the implementation of a community care policy. The availability of friends and neighbors to provide support is sporadic and dependent on material circumstances, proximity, length of residence and stage in the life cycle. The constant public debate concerning DHSS financial scrutiny and cost cutting is in stark contrast to the private costs of different health policies. The community care policy is essentially a policy which relies on the individual and the family to take responsibility for health care. It implicitly expects the individual to become an 'active participant ', or a health care 'consumer'. An examination of the structure and function of the family provides the context in which lay care takes place.

The family constitutes a moral economy, which is rooted in its

legal, economic and social structure. The basis of caring, in the family, is founded on duty, love, and obligation. Caring by the family is also reinforced by the expectations of society, by doctors, social services, and by friends and neighbors. Just as economic and social factors determine that the family should provide care, material, ideological and gender forces influence 'who' within the family cares. In contrast, caring by neighbors or friends is dependent not only economic factors but also on proximity, length of residence and stage in the life cycle. Neighborly reciprocity is not bound or reinforced by outside agencies, it is rather, bound by levels of mutual reciprocity which are established over a period of time. However, the kinds of care which the family and friends and neighbors can provide are dependent on the social and economic characteristics of the family and the neighborhood.

Family units have a set of common characteristics which are rooted in the functions which the family performs and are reinforced by norms, legal structures, and economic and social policies. Primarily, the family acts as a social, welfare and economic unit which is central to the survival and welfare of its members. Only one of its multifarious functions is health care. Health care therefore takes place in the context of fulfilling other roles. The multiple functions, which the family fulfills, link it to the wider institutions

of society, through the labour force, and through the health and education system. The family is in each case the 'lay' person in relation to professional experts. It also is a 'private' unit dealing with numerous formal institutions. In this sense the family is a 'generalist' institution.

The multifarious functions of the family also entail a multitude of roles. Spouses are not only wife or husband, but also employee/housewife, father / mother, son / daughter and lay educator, lay nurse/doctor, and lay welfare agent. In the context of caring for a dependent, convalescing patient' family members experience conflicts in fulfilling these different role obligations and commitments. While the relationships within the family are reliant on their members fulfilling certain interpersonal obligations and duties, some family members may be employed and tied to formal organisations and routines. The multiplicity of these roles and functions have two implications for health care. Firstly, that two or more roles may conflict with each other in terms of time and outside obligations and secondly, the roles within the family are not based on any expertise or particular knowledge. In contrast, to the specialised nature of hospital care or statutory professional care, the family lacks the specificity of health care as a functional single goal. Rather the generalist nature of the family forces it be a transactional unit. A unit which accesses professional care

at appropriate times and provides lay care within its particular constraints and rationales.

As Graham so cogently states;

"Caring can't be explained wholly in terms of psychodynamics - whether located in the relationship between dominant or subordinate ... it is constructed through a network of social and economic relations within the home and the work place."

[Graham,H., 1984 p.21]

Lay care within the family is also about family relationships. Caring in the family is both 'caring for and caring about' it is both an activity and a feeling. [Boswell,D.,1985] Family relationships are governed by sets of intimate role relationships which have no formal rules or professional ethics dictating the kinds of tasks which should be performed and by whom. The norms of caring, in our society, mean that women have more experience of acting as carers than men. Nevertheless in the family, unlike the hospital, convalescing patients are members of the family in which there are taboos governing relationships. For example, Mrs. McLay [spouse of # 28] was willing to help her husband with personal tasks on a routine daily basis, tasks which were necessary for everyday life. In contrast, Miss Lyle's [#25] mother was not prepared to become involved in problems associated with daily hygiene of her ileostomy. The tasks which are considered

'appropriate' to perform will vary with the nature of the relationship; whether it is for a spouse, for a daughter, for a mother, father , brother or other relative. Family members may refuse to take on certain personal caring tasks because they feel too squeamish or be unwilling for other personal reasons. The secondary nature of hospital relationships, treat patients primarily as individuals with a medical complaint and have no such complexity of taboos regarding care. The relationship is one of professional to lay and it therefore allows for what would otherwise be intimate knowledge between strangers. It is precisely the complexity of these rules governing caring, and who cares for who, which makes caring in the home potentially more difficult.

Attempts to characterise the nature of lay health care have proved difficult due to the very diversity of lay beliefs. Graham argues that lay health care is the 'promotion, maintenance and teaching of health care which takes place in the home under the direction and control of family members, particularly the mother.' [Graham,H.,1979] This definition reflects the difficulty of characterising lay care because of its unbounded, unspecified and generalist nature. It is, fundamentally different from professional care. The fact that the type of care in the hospital is fundamentally different from lay care in the home is reflected in the comment by one patient;

"Home is comforting and personal. In hospital you get care, but at home you get love and attention".[# 23]

Another patient remarked;

"In hospital you get medical care and at home you get general personal care".[#42]

The difference of lay health care from professional health care is partially due to the fact that it takes place in a different 'work setting' and it also has no cohesive, structured set of concepts of health. The fact that lay health knowledge is not based on a prolonged period of training, based on a scientific rationale distinguishes it fundamentally from professional concepts of health, disease causation and medical intervention. Furthermore, the relative isolation of the home, unlike medical training or medical practice, does not provide the opportunity for lay people to make comparisons or to evaluate their own health practices in relation to other cases or health outcomes. Individual or family experiences are more likely to be viewed as an individual experience in the home. It is not seen or experienced as one of a group of cases, with common problems, common fears and common techniques for management. Thus individual notions of health and disease and combined with the isolation of the individual

experiences make lay health care both more diverse and more generalist in its nature.

Lay concepts of health care are derived from 'common sense' ideas and from diverse circumstances and experiences. In addition, the medical profession is increasingly disseminating 'scientific medicine' through the education system and the media. Thus, while lay people may evaluate health or ill health within different frameworks or settings to medical people, "lay knowledge may consist of images or stereotypes that have been generated through official ideology" [Calnan, M. 1987, p.9] Thus lay care is composed of a mixture of knowledge transmitted by the medical profession and it is interpreted within the perceived rationales within the home.

Techniques for intervention in the home, often expresses itself in terms of changes in life style behavior, such as beliefs and control over diet, exercise, and identification of appropriate health services utilisation as well as the implementation of medical advice. The study of lay health care, in the community, is concerned with concepts of health, the causation of ill health, compliance, responsibility, the role of the individual, health professionals and the state .

In this study the main means patients and their carers

perceived control over convalescent care revolved around food, rest, exercise regimes and medications as well as 'following' the doctors orders. These ideas were not only regarded by the patients and their carers as central to the restoration of health but they were further legitimised by the recommendations of the doctors. Control over diet was regarded as the central method for the restoration of health. This is exemplified in the case of the patient who had completely lost her appetite after discharge. Her husband [spouse of #7] was most anxious. He said;

"How is she going to get better if she doesn't eat? I've tried buying all kinds of light food which would tempt her but she is just not eating. I've started buying body building products which should have all the required vitamins and protein".

Similarly an elderly widower said; [#9]

"Oh yes, you have to eat properly, everyday I cook myself a bit of meat, some greens and a potato. You should eat a proper diet."

Some patients had been told during their hospital stay to alter their diet. Families and particularly the patients had to rethink their patterns of food consumption. The dietary advice varied in relation to the diagnosis. For example, diabetic patients were told to eat small frequent meals and

to avoid sugar in any products. Heart patients were told to change to low fat, high fibre diets. Mrs. Kay, [spouse of #43] for example, purchased and prepared special food for her diabetic husband. " I prepare his dinner for him. I weigh out all the amounts because he is only allowed so many ounces of meat, vegetable and carbohydrate everyday. I prepare another meal for myself." Heart patients introduced more fresh fruit into their diet and reduced fatty foods.

The balance between rest and exercise was a more ambiguous relationship. Patients generally regarded exercises as 'being good' for one but for patients it was too painful. Patients who had major surgery found any movement prohibitively painful and they 'prescribed rest' for themselves. As one lady remarked;[#23] " I am just waiting for it [the wound] to knit together again. If I move I might be pulling at the internal and external stitches".

For the convalescing heart patients it was a prescribed part of their health care upon discharge. However, the heart patients were frightened that too much exercise would trigger another heart attack. Having experienced the pain of one heart attack, patients felt that they were on a delicate balance between taking too much exercise too soon, or not enough. However, not all the patients who had a heart attack or cerebrovascular problems followed the steady progression of

increasing daily exercise. Several of the elderly patients remained sedentary, while other patients found that breathlessness and occasional chest pains made them wary of taking exercise.

In addition to controlling 'lifestyle behavior' patients after discharge, became responsible for their daily medications . The medications which patients had been told to take or the medical procedures, which patients were expected to follow, varied in complexity. In some cases patients only had to take one tablet twice a day. However in other cases patients had to take a multitude of tablets at different times of day, before and after meals. One patient, Mr. Evans [#19], not only administered his own tablets but was responsible for setting up and taking his own intravenous food. He took the food bag, and all the equipment to his home, where he connected himself up to the food line for seven hours a day. Other patients had to become familiar with caring for an ileostomy or administering their own insulin injections. The patients 'followed the doctors orders' to the best of their ability.

The almost exaggerated sense of compliance was evident in the case of one patient when he said; [#22]

" If the doctor told me to take rat poison I would take it."

It reflected the deference and absolute trust and gratitude which patients felt for the doctors as they were recovering. The fact that patients held the doctors with so much trust was also evident in the fact that many patients were not sure of what tablets they were taking or what they were for. As one patient said [#24] " I take one heart tablet everyday. I have a slow heart beat. I take one for keeping the swelling down but I don't know what the others are for.... they don't give you any explanation of what they are for."

Apart from buying over the counter drugs patients also had little choice with medication other than to stop taking prescribed medicine. The power of the medical profession is retained, in the home, through their control over the types and amounts of drugs. Medication, nevertheless, caused some problems in a few cases. For example, Mr. Robbin's,

[# 42] heart problems and edema were, he felt, being exacerbated by one of the tablets he had been prescribed. He was weaker, had a temperature and was losing his appetite. However, he was reluctant to stop taking this tablet without the permission of the doctor. After a week, his wife asked the doctor to make a home visit. The doctor did visit Mr. Robbins and did in fact prescribe an alternative tablet.

Mrs. Terance [#24], similarly, felt that the water tablets she was taking were causing her to become incontinent. She however, decided to halve the quantity she had been prescribed

to take. Although she had intended to ask the consultant she had forgotten to discuss it at the six week follow up consultation.

The fact that the medical profession has control over most medicine is reflected in the fact that patients have to visit the doctor for any questions concerning their medications. They have little knowledge with which to evaluate the medical advice. The decision to visit the general practitioner is often difficult for patients. As a result of the isolation of the home there is no comparative basis by which patients and their carers can evaluate the effectiveness of the quality of the care they receive or the progress they have made. Patients often made comments to the effect ' I want the doctor to tell me how I'm getting on'.

Patients decisions to go and see the doctor were influenced by a variety of factors. The availability of a car, the degree of isolation, their mobility, the severity, pain and their relationship with their doctor are all factors which influence 'going to see the doctor'. The considerable literature on 'going to the doctor' has consistently shown social class differences in utilisation. It is argued that the lower social classes use the primary medical services less than the middle class and emergency services more. It is argued that the lower social classes have less familiarity with scientific concepts

or medically approved knowledge. Furthermore, it is more likely that the working class person will enter a consultation with the doctor when there is real pain or discomfort, while middle class people are more likely to seek medical recommendations before symptoms become acute. For this reason it has been speculated that the working class are more likely to enter the hospital under emergency care than their middle class counterparts. Raphael's [Raphael,E., 1964] study, for example set the 'agenda' for a closer look at utilisation and social cohesiveness of the community. She found that rates of utilisation were lowest in community areas with residents who had comparatively little education and were long time residents and highest in communities, with well educated, mobile residents.

The study by Miles [Miles,P.,1983] in Milton Keynes found the significance of 'length of residence' as a factor in patients decisions to consult the doctor. His study concluded that patients regardless of social class were more likely to visit the doctor if they were new to Milton Keynes. This was confirmed in the work of the Milton Keynes Dept. of Community Medicine [MKHA, 1987] on the underprivileged areas of Milton Keynes, which showed that newcomers to Milton Keynes was the most significant factor in determining the workload of general practitioners. In this study, all the patients contacted the general practitioner with their discharge letter within two

weeks post discharge. However, there was some evidence that those patients who called the general practitioner frequently were those patients who were very anxious about their condition, particularly if this was combined with social isolation. Newcomers to Milton Keynes were more prone to call their general practitioner, if this was combined with anxiety about their condition. Furthermore, conditions, such as heart attack, which have come to reflect individual culpability engender greater anxiety in after care management and therefore predispose these individuals to seek greater contact with medical professionals.

Feelings of acute anxiety as much as objective symptoms typically precipitated calls to the doctor. Ball's study 'Going Home after a Heart Attack ' [Ball,J. 1986] found that many patients suffer unnecessary disability due as much to fear and to anxiety as to organic disease. In one case, a patient [#33] felt that she had not been properly diagnosed because she was continuing to experience swelling and pain in her neck after discharge. She therefore made frequent contacts with her doctor and also actively pursued alternative medicine and physiotherapy. However, for those patients, who could not drive or had no available transportation and lacked sufficient mobility to use public transportation, visiting the doctor was a major difficulty, which required the assistance and cooperation of others. Transportation difficulties,

however, were not the only factor which deterred patients visiting the doctor.

The relationship patients had with their doctor was also an influential factor in how easily they would make an appointment. Some patients felt that they had a very good relationship with their doctor. They felt that their doctor understood them and he was a personal friend. This was a great comfort for these patients. However, in a few instances patients felt that they could not get along with their general practitioner. In one case, in particular, this was a source of great anxiety because the patient felt very dependent on the G.P. for advice and support. He was, afraid of the power of the medical profession and this was reflected in his comment ;" You don't want to get on the wrong side of the doctor" although he clearly felt he was.

Although rest, diet and taking the prescribed medications were central to convalescent care, it was also the case that patients who had practiced 'bad' health behavior experienced feeling of responsibility and guilt. The medical profession and health educators have influenced the public to accept individual, moral culpability for heart problems. Specific diagnosis influenced perceptions of culpability. Heart patients were more likely than any other group to express feelings of guilt. Those patients who felt 'morally'

responsible for their ill health were often anxious to control those habits which they thought to have caused their ill health. Heart patients gave up smoking, they increased their level of exercise, and changed their diet. In contrast, most surgical patients did not perceive themselves responsible for their ill health. Illnesses such as appendicitis, gall stones and cancer of the bowel were not stigmatised as life style illnesses. These patients did not express the need to alter their diet, exercise or habits. For these patients the cause of their ill health was not identifiable and concomitantly the means of perceived control was less.

Although the interviews show a great deal of uniformity about convalescent care, there were also noticeable differences. Among the large number of patients who experienced a heart attack, for example, there were variations in the degree to which patients perceived it to be as a result of their life style and their responsibility. This was expressed in their feelings of culpability. Feelings of responsibility for their own ill health was more evident among younger patients than the elderly. The younger patients were more likely to be aware of the publicity surrounding the health care movement and current medical philosophy on individual responsibility for health. The elderly were more likely to have the attitude which normalised ill health as an inevitable outcome of old age. A few cases will illustrate variations in patient

attitudes.

Mrs. Compton [# 30] is an active 60 year old who scarcely acknowledged that she had a heart attack. She did not read the literature provided by the hospital on 'After a Heart Attack' and at home she continued with her hectic pace of redecorating their new house. Her attitude was 'you can't sit down to this'. In contrast, three professional men displayed a more organised approach to their self care at home. Mr. Nollins [#26] wrote out his agenda for each day, quit smoking and made daily increments in his level of exercise. Mr. Stromber [#34] and Mr Sharp [#18] attributed their heart attacks to smoking and eating fatty foods. They also quit smoking and made changes in their diet and took regular exercise.

In contrast, Mrs. Taylor, [#24] an elderly lady seemed to sit in her chair and watch T.V. She appeared vague and distracted. She expressed little interest in her heart condition. Ill health had been experienced by herself and her husband in varying degrees in more recent years and the implementation of a pace maker was viewed more as an inevitable outcome of old age and declining health.

Mr. Hume, [#9] an 80 year old gentleman, scarcely worried about his health other than to eat a balanced diet and to take his medications. He said rather than worrying about a bit of

ill health, he in fact felt "for my age I'm in very good health".

Numerous studies have attempted to explain differences of health beliefs, utilisation of the doctor and social circumstances [Blaxter, M. and Patterson, L. 1982, Calnan, M. 1987, Cartwright, A. and O'Brien, M. 1976 and Freidson, E. 1970]. Material and cultural explanations have frequently been put forward to account for the diversity of family health experiences and the nature of lay care. In more recent years there has also been an increasing emphasis on the role of the individual in health promotion. Indeed, it has been argued that the community care policy has this as a hidden assumption. Patterns of ill health remain constant, however, the explanations offered to account for health inequalities differ. The structural approach emphasizes differences in housing, employment, incomes and related constraints. Constraints which have been identified to influence health behavior include resources such as time, energy and finances [Townsend, P. Davidson, N. 1982, Graham, H. 1984]. Another set of explanations which attempts to identify the diversity of health behavior is based on cultural factors. These explanations focus on culturally transmitted beliefs. One example of this is the theory of the 'cycle of deprivation'. This theory argues that poorer groups have their own set of values and knowledge which are different from mainstream

society.

Material factors which are known to influence health care include income, employment benefits, social security benefits, pensions, housing quality, and the ability to purchase adequate food and warmth and a car or public transportation. Graham [Graham,H.,1984] argues that one of the prime factors shaping health routines are material constraints. For low income families compelling and often conflicting choices are made between rent, fuel, transportation and household bills. Decisions can not often be made on optimal choices but rather as a matter of practical urgency and immediate need. In contrast, cultural theories have concentrated on the life styles of the least well off. It is argued that the lower social classes do not practice health behavior which is congruent with middle class professional's future orientation, values of individual responsibility and self discipline. It is as a result of this approach that modification of health beliefs through education is often suggested as an appropriate policy.

The categorisation of theories into structural and cultural explanations is, however, an over simplification. It attempts to delineate aspects of individuals lives into disparate realms as if in everyday individual's lives material circumstances and cultural beliefs were independent. Clearly

material and cultural explanations can complement each other. Evidence suggests that there is a logical interaction between material and cultural factors interacting to influence health behavior. Graham [Graham,H., 1984] argues that the lower social classes are acting in a way which is rational and functional in the context of their own circumstances. There is recognition that far from being random or idiosyncratic the knowledge, attitudes and lifestyles of the poor can be viewed as consistent and understandable responses to problems associated with their position in the social class structure and life chances. Thus in contrast to the cultural theory which characterised the poor as living in a low level of social organisation, helplessness, and dependence , Graham argues that, in fact, the lower social class behave rationally in view of their differing practical and material constraints. For example, Graham found that smoking, an otherwise 'bad ' health practice , was a practical release from tension for many poor mothers. These working class mothers had few alternatives in terms of time or financial resources to seek the release from stress and to maintain, at the same time their responsibilities as mothers. For them, smoking was a necessary release and functional behavior in their circumstances. This would lend support to the argument that utilisation, health behavior and inequality lies not in the direct costs but in a rational weighing of perceived costs and benefits of attendance and compliance with a particular

regime. The material and cultural explanation suggests that the costs and benefits will be perceived differently by the middle class and the working class. For example, using public transportation results in more time being spent travelling and therefore taking time from work to use the public transportation service to medical appointments may result in a loss of income and consequently a smaller probability of attendance. Professional work allows a flexibility in the organisation of time and work to allow at no financial impairment to patients or their carers to attend appointments. Blaxter and Paterson [Blaxter, M. and Patterson, L., 1982] found in their study of mothers among the lower social classes that the circumstances of women's daily lives inevitably affected the way they perceive their children's symptoms, their use of services and their attitudes to health. There were minor ways in which a family health culture could be demonstrated and its direct transmission from grandmother to mother. It influenced set ideas about feeding, fear of particular complaints and beliefs about 'lying down to illness'.

Calnan's [Calnan, M., 1987] study illustrates the interaction of social class and concepts of health, causation of ill health, the responsibility for health by the individual, the general practitioner and the state. Calnan found differences in social class perceptions of the distribution of ill health and the explanations for this. He found that definitions of

health varied between social class I & II women and those in social class IV & V. Social class IV and V were more likely to define health as 'getting through the day or never being ill' , whereas social class I & II defined it in terms of feeling strong, feeling fit and being energetic". Therefore it would appear that the central difference in what constitutes health is that the middle class conceive of it in positive terms whereas the working class conceive of health in passive characteristics and the absence of symptoms. Calnan also found that middle class people believed the poor to be in poorer health because of environmental, personal factors and lack of information. The working class, in contrast, were more likely to believe that the rich were in worse health because of overindulgence and that working class was not in worse health than the middle class.

In contrast, to the different opinions on social class and the distribution of ill health, concepts of disease causation have a greater homogeneity among the middle and working class. Blaxter's study found that 'despite differences in education, medical knowledge, experience of illness and responses to stress or to uncertainty there was a greater similarity of response than diversity' [Blaxter,M. 1987,p. 220]. Blaxter found that the major feature of patients' accounts of their illness was to attempt to see their experience as a whole. Blaxter found that patients were attempting to provide a

coherent story. Similarly, patients in the Milton Keynes sample, expressed feelings of isolation, depression and a wish for counselling in order to help make sense of the illness episode. Blaxter found that patients preferred to think in terms of environmental or behavioral causes of ill health, rather than physiological explanations. Calnan's study, for example, supports this finding. He found that heart disease was identified with stress/strain and over weight by both social classes. Similarly, depression was associated with both social circumstances and psychological make up by both social classes. It was seen as an interaction between the individual and the environment.

The evidence from this study, which can be distinguished from other studies on health beliefs because it interviews patients after an episode of ill health, suggests that general differences in lay care and health beliefs were associated with not only with social class, but also stage in the life cycle and diagnostic category. In this study, the social class differences in lay health beliefs were a question of the degree to which they varied rather than in absolute terms. The perception of individual responsibility for their own health care varied between different illnesses and stage in the life cycle. For example, in this study, heart disease was regarded as an illness which people had greater culpability for. Smoking, diet and alcohol consumption were behaviors typically

associated with illness. Nevertheless, there was a reluctance to say that the individual was always to blame but rather that ill health was associated with hereditary and environmental factors also.

Retired patients were more likely to view their illnesses as 'the wearing out of the body', and as a natural progression of old age. Younger age groups, in contrast, were more likely to view their illness as a result of poor health behavior. Blaxter's [Blaxter, M. and Patterson, L., 1982] longitudinal study confirms the importance of generational differences. The longitudinal study found differences between generations among lower social class women in relation to their attitude toward medicine. Blaxter found that the younger generation took a more scientific attitude toward medicine. They expected more from medicine and were typically more knowledgeable. They said things like " I don't want him to just examine her I'd like him to put her in the hospital for a cardiogram". The older generation had lower expectations and less initiative in seeking, mediating health care advice. This suggests that the general level of publicity and health information for specific illnesses has been effectively disseminated, but it may take a generation for it to become implemented.

This raises the question of perceived responsibility between the individual, the general practitioner and the state. The

work of Calnan found a diversity of opinions. It illuminates the diversity of opinions which lay carers have of their responsibility vis a vis other institutions in society for their health care. This becomes increasingly important as health care becomes increasingly placed as a responsibility of the family. Calnan found that the middle class and the working class had a different conception of the role of the state. The working class felt that the state should take a more actively interventionist role. They particularly felt that the state should be involved in the financial intervention, such as raising pensions. The middle class, in contrast, felt that the role of the government was as an educator. The middle class were committed to the idea that education would facilitate personal responsibility. The working class, in contrast, seemed to be suggesting that financial restrictions prevented them from implementing better health care. The working class perceptions are an interesting in comparison . On the one hand, they did not feel that they suffered worse health than the middle class, on the other hand, they felt it was financial restrictions which prevented them from having better health. Furthermore, in the light of the statistical evidence documenting increasing ill health with declining social class, the working class perceptions are an interesting contradiction.

The role and responsibility of the general practitioner as an

educator in Calnan's study was not found to be significantly different between the social classes. In general, the general practitioner was viewed as being too busy 'curing sickness' to spend much time giving preventive health care and educational advice. However, the majority of women felt that the general practitioner should devote more time to offering this type of advice. In the case of convalescent care, patients approached their general practitioners with a whole range of problems, such as employment problems, social problems to medical problems. However, few patients mentioned that their G.P. gave them advice on lay care or on diet, exercise or recommendations for self care. If patients were given this advice it was usually during their hospital stay. In addition, the Milton Keynes patients thought that their G.P. was too busy to visit them in the home and that convalescent care was up to themselves. However, some patients expressed the opinion that 'the doctor is responsible for my health' and he should see to it. Furthermore, regardless of social class the medical profession has the power and authority to legitimate the actions or advice, which patients or their families gave themselves.

IV. Conclusion

Community care philosophy is premised on a changing relationship between patients and their doctors; it is based

on clinical practice becoming increasingly subordinate to administrative, and financial control and a rejection of the bio-medical model of health in favor of a bio-psychosocial model of health. It is one which emphasizes individual responsibility for health prevention , health maintenance and after care. The juxtaposition of the structure and organisation of hospital care and community care highlight their different characteristics and the implications for convalescent care in the community.

It has been argued that the hospital and the family in the community are in obverse relation to one another. The features of institutional care revolve around the capital concentration of professional and technical resources and the efficient use thereof, with patients as the 'objects' of this service. In contrast, the community care policy is composed of statutory formal and informal sources of care with the patient as the organiser of care. Thus the organisational and financial features of the respective institutions; the hospital, the community statutory services and the family exhibit essential differences which affect how the 'patient' is treated , what they are offered, the responsibility which the individual has, the environmental circumstances in which care is offered and the rights and obligations under which care is offered. These are reflected in the essential differences in lay and professional care. Each of these characteristics has a

penetrating impact on the nature of the care provided. Both the hospital and health centers share in common a statutory services based on professional expertise. This contrasts sharply with the generalist nature of care provided in the home. The essential characteristic of acute convalescent care in the community is that there is a disparity between what people feel themselves capable of and what is expected of them by the professional services, there is a 'competence gap'. It is clear that patients enter into the 'quadrangle' of responsibility both as 'objects' of the service and increasingly as the 'consumers' of the statutory services. Nevertheless, the role of consumers of the 'professional medical services' presupposes an active, knowledgeable and informed patient. It is premised on a greater uniformity of knowledge and material and social circumstances than exists in the community. In fact the diversity of the use of preventive health care practices, differences in health beliefs and differences in the utilisation of health care services is in fact so disparate that it leads one to question the advisability of a policy, which in practice, is based on family health care, influenced as it is by material circumstances, ideology, gender and cultural factors. The fact that these factors influence both the nature of lay health care and 'who' provides it suggests that there is cause for concern. Just as there has been acknowledged concern among the medical profession and among health planners and medical

sociologists about the use of preventive health care services there should also be concern about the after care of convalescent patients in the community.

Chapter 9

Setting Acute Care on the Health Care Agenda

"Community care in relation to specific client groups has been the subject of considerable attention but much less effort has been devoted to an overall analysis of the development of community care"... "Early discharge ... schemes should not be introduced without full consideration of their impact..." [DHSS, 1981a p. 46 & 49]

Comparatively little research has been conducted on the care of acute patients in the community. It has been the goal of this research to explore the needs of acute care patients vis a vis the community care policy. The present study challenges the limited concept of Community Care. Research on the discharge of patients from acute care wards demonstrates conceptual and practical problems with the community care policy as it currently stands. At a general level these problems stem from the earlier discharge of acute care patients into the community without a recognition of their needs. The more specific problems of community care for acute convalescent patients pertain to their informal and formal aftercare. The research highlights the interacting roles of

medical care in the community and the relationship between the hospital, community medical professionals and the family. It raises questions about the provision and the distribution of health and social services as well as the relationship between professional and lay health care .

Specifically the research in this thesis has challenged the accepted notion of the 'priority groups' as being too restrictive a category in community care. The concept of community care has so firmly focused its attention on the elderly, the disabled, and the physically and mentally handicapped that it has failed to consider the needs of those discharged from acute care wards. The research has demonstrated that the policy of 'community care' 'the transfer patients from the hospital and long stay institutions to the community', is being applied not only to the 'priority groups' but also to acute care patients. The concern therefore is for the well being and support of acute care convalescing patients, who constitute a large fraction of hospital beds and have the highest hospital throughput. It has been established that the Oxford Regional Health Authority and the Milton Keynes District Health Authority are at the forefront of health care policy. Milton Keynes District General Hospital, in particular, has established a fiscal health policy which reduces the cost per hospital patient by pursuing a policy of earlier discharge. The MKDH has recognised the need for longer

care of some elderly patients in hospital and they have therefore created special 'geriatric wards'. These 'geriatric' patients have been defined by professionals in the hospital to require a longer than average length of stay for medical or social reasons. In contrast, general medical and surgical patients are patients of all age groups, 18 years and older, who, however, do not receive special discharge planning. The emphasis on the elderly and the other priority groups obscures the large numbers of acute patients in the 45 to 64 year old category. The 45 to 64 year old age group constitutes, as such, a forgotten generation of health care recipients.

The interviews sought to establish the magnitude of the 'problem' of acute care in the community; to identify what acute ill health meant for the convalescing patient; the social and material context in which lay care took place; 'who' cared for the convalescing patient; and 'what' they were able to provide. The interviews also sought to identify the nature and delivery of health care in the quadrangular relationship between the hospital, community health and social services and the family.

The research found that several problems emerged as a result of the study of acute care which had not been raised in earlier research on community care . Specifically, the study of acute care found important differences in stage of the life

cycle and attitudes to health care management post discharge. It found a significant relationship between the availability of 'main' carers and the relationship to the patient to differ with social class as well as stage in the life cycle. The research brought to the forefront of health care issues, the inescapable relationship between ill health and the social and material environment, an aspect of the community care literature which has been under researched and poorly developed.

The study of acute care highlights the close epidemiological relationship between ill health and social class. The work of Townsend and Davidson [Townsend, P. and Davidson D., 1982] and statistical tables produced by the CSO [Regional Trends, 1985 and General Household Survey, 1984] indicate that morbidity and mortality are, for most illness categories, likely to occur earlier for the lower social classes than the middle class. Factors such as housing, employment, income and transportation are most often cited as the material and economic factors which influence health care. Social factors are also influential in health care due to the central role that families have in supporting , tending and negotiating health care for family members. The interviews of the discharged patients supported existing studies of the relationship between material standards and health. Material standards, such as housing quality, and disposable income ,

access to transportation and employment affect the quality of lay health care. They influence the perception of accessibility to the doctor and 'who' provided care. Furthermore, ill health accentuated existing inequalities by aggravating problems with employment and incomes among economically active individuals and their carers.

The Jarman scale established housing quality to be a least significant factor in the case of Milton Keynes. This is due to the large new housing stock built in Milton Keynes. The new city housing stock is of a high standard and does not have some of the problems associated with deteriorating inner city housing. However, some of the older areas of Milton Keynes housing, much of which is owned by elderly people, has deteriorated. Therefore the owner occupation as a category needs to be taken into consideration in conjunction with the age structure of the area and the housing stock [Source : Milton Keynes Urban Studies Center, Milton Keynes Census]. In the case of Milton Keynes it was therefore appropriate to dismiss the usefulness of housing tenure in the Jarman scoring. In addition, housing conditions are not of sole importance to convalescing patients, the disabled, the elderly and acute care patients. Housing design is also of importance to individuals who have difficulties with mobility. Many of the discharged patients were primarily confined to the ground floor of their homes for two to three weeks post discharge.

Only a small number of patients remained totally confined to the ground floor six weeks post discharge.

Transportation is a significant factor in health care and this is particularly the case in Milton Keynes. Transportation is vital not only for accessibility to the hospital or the health center but also for shopping, for outings and for visiting friends and relatives. The research found four groups of patients with transportation difficulties. One group of patients did not own a car due to the lack of financial resources. These patients were primarily either the elderly or the unemployed. The elderly and the unemployed patients were reliant on the availability of relatives, neighbors or friends to take them to the health center or the hospital. It was frequently the case that their relatives or friends lost income for the time they were driving their relative to the doctor. Another group of patients, who did not have transportation, were patients who had suffered a heart attack. They were prohibited from driving by their insurance company policy. These patients were not insured to drive for at least six weeks post discharge. Spouses, particularly women, did not necessarily have a licence to drive their convalescing husband and therefore these couples were reliant on other sources for transportation. In addition, many surgical patients were suffering too much pain to be able to travel in a car. The vibration and stopping movements created too much stress on

abdominal wounds. The final group of patients who had trouble with transportation were a number of elderly couples who were car owners however they felt themselves to be reaching the stage in their life where driving was no longer safe for themselves or others. Thus, the lack of transportation is closely linked with the problems originating with age, ill health and low incomes. The community care policy however relies heavily on the family to organise, initiate and access health care. The problem of transportation should be an important variable in identifying community health needs.

The type of employment which patients and their carers had was an important factor in the organisation of providing care. The constraints imposed by different occupations influenced the availability of spouses to care and it influenced the security of employment and income for patients and their carers. In the normal course of events spouses made arrangements to care for their wives /husbands. Due to the epidemiological distribution of ill health, however, it is the case that women in the younger , economically active age groups will be more likely to care for their husbands and this is particularly the case in the lower social classes. Among the retired age groups women live approximately ten years longer than men. Retired professional men and women live longer than those who had been employed in working class occupations. The implications of this data are twofold. Women,

quite apart from economic or ideological reasons, are more likely to care simply because of the distribution of disease. Furthermore, given the distribution of disease, working class women are more likely to provide care for their husbands. In the cases where a working class, economically active, husband is responsible for looking after his wife it is more likely that a 'substitution' will occur. In these cases, it is more likely that a daughter will provide care, even if this means that she has to give up her employment or reduce her working hours. This 'substitutability' is more likely to occur with daughters than sons. This is due to both economic and ideological factors. Women have the least secure and the least well paid occupations, such as serving in a school canteen or as a cleaner, which means that the loss of their income makes a smaller impact on the family. The arrangements for a main carer were more difficult where the main breadwinner's occupation required strict time keeping; such as shift work and those occupations with restricted fringe benefits for holiday time etc. Typically these occupations were working class occupations, precisely those which are associated with higher levels of ill health.

Thus inequality in health care does not only revolve around direct material standards of living but also on the availability of a main carer. It has been argued that 'who' the carer is, is a result of economic, and ideological factors

as well as gender, and stage in the life cycle. The differences in problems which these respective groups encountered reflected their stage in the life cycle and their position in the socio-economic structure. Among economically active couples 'substitution' was more likely to occur for working class husbands. Middle class husbands and the elderly could arrange the time to be home to provide care or were normally at home. Among the elderly, spouses if they were still alive, provided care. However for the elderly, the problem of the carer's health became more problematic. The carer was often also suffering from minor or chronic complaints. In contrast, among the economically active the data indicated that employment benefits affected 'who' provided care. It is, therefore, working class women bear the brunt of the community care policy, both statistically and economically. Statistically, this is a result of the distribution of ill health. Economically, it is due to the fact that the loss of income from their employment affects the family less than that of the breadwinner.

Among retired couples the effect of material, ideological and gender influences plays a less pronounced role. Retired couples, share household tasks and caring for each other. Retired couples have more time and this brings about a new division of labour in the home. Employment income does not act as a factor in their caring arrangements. Rather the

combination of greater amounts of time, and the fact that economic and sexual division of labour is less significant , retired couples have less genderised roles. Caring functions are dependent more on health and physical status than by ideological or economic imperatives.

Patients living without a main carer, were very dependent on their children to care for them. Among the elderly, this meant that their 'children' were in their late fifties or early sixties and still economically active. Their 'children' frequently did not live close by and therefore contact was not on a daily basis. Divorced patients, in the economically active age group, were dependent on their teenage children. While the economically active 'children' may have found it difficult to care for their elderly parents , teenage children were often too busy with their own lives to provide much assistance or comfort. Nevertheless, only three of the nine patients living on their own, received help from social services. The three male patients, two of whom were elderly, received home help visits two times per week. The limited availability of home help highlights the continuing practice of allocating limited social service support for the men, particularly elderly men.

Thus the examination of 'who' provides care illustrates the influence that the stage in the life cycle has with caring as

an activity. The respective stages of the life cycle are associated with felt or imposed constraints which direct particular people to provide care. Over the life course there is an interaction between stage in the life cycle and material standards of living. The stereotype is that the elderly suffer both declining ill health and material standards of living. However, in the sample of patients interviewed, disparities in living standards were just as pronounced between the elderly as they were between the economically active couples. Indeed patients living on state pensions and patients living on state social security benefits encountered similar financial problems. Patients who were retired with additional employment pensions generally enjoyed a higher standard of living and a better quality of life than those patients who were unemployed. They generally owned and operated a car and could afford occasional diversions from the normal routines of their life. Furthermore, retired couples encountering an episode of ill health did not face the financial threats which are the preoccupation of the economically active working class couples. The crucial problems for economically active patients were the loss of income or their source of employment. This was particularly important if they also had dependent children. The problem which the elderly were more likely to encounter was with the health of their spouse. In those instances where there was no main carer, in the household, patients were more likely to require the assistance

of the social services.

Thus, the research findings lend support to existing literature on health inequality. It points not only to problems in direct material costs but to the interaction of material, economic and social circumstances which are affected by caring arrangements. The problems for patients and the main carer do not lessen but simply change during the life course.

The differences between patient's social and economic circumstances need to be considered in relation to their common needs. The interviews with patients demonstrated certain common problems which patients discharged from hospital encountered. These common problems could be differentiated in relation to the provision of services. Three types of needs can be identified. First, the majority of patients had 'hotel' needs such as requiring assistance with cleaning, cooking and shopping. Secondly, some patients also had personal care needs, such as using the toilet, bathing and getting dressed. The third type of needs are concerned with the medical regimes which patients must follow once they have been discharged from hospital. These may involve changes in life style behavior and following a course [or courses] of medication. It was found that regardless of diagnostic category patients uniformly had hotel needs upon discharge. Very few patients were capable of looking after the running

of a household or able to prepare food. The common problems were lack of mobility, pain, depression and anxiety. In the severe cases, patients were in need of 'personal care'. They required physical assistance due to the lack of mobility and pain which they experienced. A comparison of all forty-five acute care patients, young and old alike, with the 'elderly at home' found that their needs are more severe than that of the elderly at home. [Hunt,A., 1978] This is particularly the case when comparing 'hotel' needs of those discharged. The first week home was the most difficult. Patients lacked mobility and were anxious. Six weeks post discharge found a marked improvement in many of the patients, nevertheless many of the patients were still suffering from restriction of activity and depression. Some patients had recovered only very slowly and a few patients were readmitted.

The distinguishing feature of acute care patients, discharged from general medical and surgical wards, are the medical needs and medical regimes which they are directed to follow . The inexperience and rapidity of the ill health episode leaves patients unprepared for caring for themselves and coping with the emotional trauma once they are discharged. They experience a continuing need to account for their episode of ill health. After discharge patients were expected to follow the directions of the consultants. These directions took two forms. One is that patients are expected to follow a

prescribed set of tablets or other medication throughout each day. The second form of instructions were concerned with the modification of lifestyle behavior, such as changing diet, giving up alcohol, or giving up cigarettes. Of the two forms of instructions, patients found changing their lifestyle much more difficult. Despite the power of the medical profession and the respect patients felt for their knowledge only 75% of the patients adhered strictly to changes in lifestyle behavior. However, the research found that patients were taking their medications even if they were experiencing side effects. Patients were also responsible for the care of minor surgical incisions. In these instances, patients were more able to cope with surgical incisions if they had previous first aid instruction. Several patients suffered wound infections after discharge and had to seek advice from a general practitioner. However, other patients were also not coping well. Patients expressed a reluctance to call the general practitioner even though they felt that they were not improving. Three patients, from the total sample of forty-five patients had to be readmitted to hospital.

The combination of patient anxiety, inexperience, lack of knowledge, difficulty with changing life style behavior, problems with medications and difficulty with fulfilling tasks in daily living point to a real need for medical and educational support during convalescence. Patients identified

landmarks in their episode of ill health. These were hallmarked by the entrance to hospital, the discharge from hospital and the abrupt transition to their home. The isolation of the first week home made a profound impact on the patients. The abrupt transition from total professional care to the isolation of lay domestic care accentuated existing anxieties. Patients were torn between the desire to be in their own homes and the wish for the availability of medical care.

At the forefront of the evaluation of the community care policy has been an examination of the role of the family, friends and neighbors and statutory community support. The success of community care relies on the structure of informal and formal provision in particular localities. Of central importance for the health care of convalescent patients is the structure of the family, the proximity of family members, and friends, the length of residence, the availability and ability of neighbors to provide care and the levels of statutory provision. The research found there was a disparity between the self perceived needs of patients and the type, timing and amount of 'community' care.

In this study , as with other community care studies, the family is of crucial importance to the care of the convalescing patient. The nature of the needs of convalescing

patients is that they require daily support, help and tending. Thus proximity is important in the after care of these patients. The evidence suggests that the nuclear family provides the majority of care for acute care patients and those discharged from long stay institutions. However, the community care policy assumes that friends and neighbors will play a vital role in community care. The research on levels of 'community' support by neighbors, and health and social services indicates a fundamentally different relationship than originally conceived in the community care literature. The notions of warm and caring communities does not always coincide with reality. While immediate neighbors are often helpful by performing such tasks as taking in the milk or perhaps doing some small shopping there also appear to be both normative expectations and normative obligations which determine or set a guide to what 'neighbors' should do. Generally neighbors can be asked to help with shopping but not with such tasks as cooking or cleaning. In none of the interviews did neighbors become involved, in personal care routines or the detailed involvement of medical prescriptions. The primary concern of patients was with their medical problems, problems which family and neighbors generally could not answer. The extent and range of help from neighbors was influenced by the social composition of the immediate neighborhood. Not only were patient needs for assistance more likely in the case where patients lived among other elderly

people, they were concomitantly less likely to receive help there. Similarly, patients discharged to communities which generally had low material standards, neighbors were less likely to be able to offer help. This was exemplified in such practical forms of assistance such as being able to offer transportation to the health center , the hospital or to the shops. In this way the material standards of living and the social composition of the neighborhood directly affected the patient in terms of the type of practical assistance neighbors could offer. Given the normative rules of 'neighboring' and the nature of services neighbors could offer materially or physically, also affects the ability of some people to help. Elderly people, for example, often do not own a car and therefore can not offer assistance with transportation. They are also often too frail to help with shopping. Similarly patients living in areas of high unemployment encounter similar problems with assistance. Neighbors may not have the standard of living to enable them to provide assistance.

The fact that the new city of Milton Keynes, has a new population, with a comparatively short length of residence, is a concern to the health and social service professions. The results, of the study, indicate that patients with the least support were the very elderly patients, and unemployed patients. Elderly or unemployed patients living among elderly or unemployed neighbors could obtain little assistance.

Elderly neighbors could offer little help with the 'hotel' or personal care needs of patients. Similarly, elderly or unemployed patients found it difficult to give or receive assistance from their neighbors. Thus, the less mobile, and the least well off, received less neighborly help. Similarly, families who had just moved to Milton Keynes, particularly in the first year indicated that they were less likely to have help from their neighbors. The necessity for neighborly help was of course ameliorated if they had other family members in the vicinity. In contrast, among those who had considerable neighborly support were those patients who had been active with their neighbors and had lived there for four years or more. For example, economically active patients, who have been active and involved with their neighbors, received help from their neighbors at this time of need. They had established and maintained levels of reciprocity which formed the basis for neighborly support. Thus at the heart of the question of length of residence is not only the objective reality of the length of residence as measured in years but also the levels of established mutual exchange and reciprocity. The process of establishing mutual exchange requires time, regular contact and ability to offer services. Therefore, the least likely to receive help from neighbors are those who are new to an area, the very dependent people who rarely go out and the least well off. In this study, those patients who had received the most support from neighbors were those who were actively involved

with their neighbors in local quasi formal or formal organisations, such as allotment associations or the church. The research, therefore, supports the current concern among health professional and community planners over the needs of the least mobile and new residents in Milton Keynes. Proximity , length of residence and level of community involvement on the part of the patient were all influential in the level of offered or actual support.

The evaluation of the current structure of formal community provision , by the Audit Commission, found that provision for the priority groups was inadequate and that receipt of statutory support was based more on availability than need [Audit Commission, 1986]. It recommended the expansion of the number of home helps and meals on wheels and a growth in the numbers of community nurses, in order to make current objectives for community care effective. The fact that the Community Care policy is being implemented, through earlier discharge, for acute care short stay patients as well, suggests two problems for care of these patients in the community. One problem is that community service provision is not being made for the after care of acute short stay patients . Secondly, it does not recognise that the needs of short stay acute care patients are different from those being discharged from long stay institutions.

The implication of current health policy is the lack of additional provision for acute care convalescing patients, particularly for the younger age groups. In the Milton Keynes hospital longer stay elderly patients were placed in the geriatric wards. These 'geriatric' patients were given additional support through the coordination of the Community Liaison Officer. The Community Liaison Officer's responsibility was to coordinate hospital and community social services. In contrast, 'young' and elderly patients discharged from general medical and surgical wards, were dependent on their families to provide after care and to coordinate professional advice. Furthermore, the orientation of community care provision is primarily aimed at the increase in the number of home helps and meals on wheels. Little attention has been directed to the provision, organisation, policy and practice of community nursing services. This creates additional problems for the care of convalescing patients in the community because of their greater needs for medical care and counselling.

The different structure and the organisation of the health and social services effects contact with the services. Social service provision is largely based on professional identification of 'need' for its clients. In contrast, the medical profession assumes a 'consumer' model which is dependent on patient identification of need and patient

initiated follow up. Medical practice relies on the patient to be the active participant. The research found that communication between the hospital, the general practitioner and the patient was weak. Hospital based doctors and general practitioners relied on patients to facilitate communication between the hospital and the general practitioner. The hospital discharge letter was mediating link between the hospital and the general practitioner. It was the responsibility of patients to bring it to their doctor. This was despite the fact that patients were feeling the least able to cope in the first week after discharge. Furthermore, general practitioners did not generally make home visits. Patients were generally not visited in their homes by general practitioners, even if patients expressed a request for them to do so. This was particularly the case for families in the new city housing, attached to the new city health centers. Professionally initiated medical follow up was provided in a limited way through community nursing services. However these services were premised on nursing criterion of need. It was provided only to those patients who had major surgery, if they had suffered several heart attacks, or were diabetic. Thirty-three of the forty-five patients did however receive a six week follow up appointment with the hospital consultants either at the hospital or at one of the specified health centers. The appointment provided patients with an evaluation of their medical progress and an opportunity to ask any

questions. The six week follow up appointment was uniformly appreciated because it provided a link between the hospital experience and their health outcomes.

In terms of the 'shared' responsibility between the hospital, the general practitioner and the patient, responsibility for convalescing patients devolves primarily on the convalescent patient and their carers. In view of the lack of mobility, medical and emotional needs patients had after discharge a shortfall of community statutory provision is indicated. As the Oxford Regional Health Authority has noted in its regional report, there is a shortage of community nurses. This appears to be confirmed by the fact that only the most severe patients received a community nurse.

The shortage of health and social service support is reflected in the policy and practice of community care, which directs limited services to the priority groups and neglects acute convalescent patients and the younger age groups. Furthermore, the provision of community nursing provision is based on medical definitions of need and this is at variance with patients self assessed needs. In addition, the data suggests that there is a disparity in the timing of patients needs and the provision of services. Taking into consideration the material , social and economic factors which promote or inhibit the use of professional medical services there is a

danger that some patients are not receiving the care which they require.

To summarise, the interviews led to a critique of the concept of total institutions and the idealistic notions of community care. The research uses the concept of the convalescent career as a sociological tool and a practical device for conceptualising a patient's admission, discharge from hospital and convalescence. The concept of a career, acknowledges that health is a biological, medical and a social phenomenon. Health and ill health are a product of social and economic circumstances as well as individual life style management. The concept of the convalescent career therefore bridges the stage in the life cycle, social and economic circumstances and individual life style behavior. It follows a 'career' over time which is marked by entrances and exits into the hospital and the community. It is not only as a heuristic device but also as a practical device for identifying the timing and nature of statutory support. It emphasizes both the commonality and the uniqueness of the episode of ill health. It places health on a continuum of the occurrence of recognised ill health, the hospitalisation, the convalescence and health outcomes. The concept of the convalescent career acknowledges that the ill health and health are shaped and structured by the institutions of the hospital, the family and the community. It bridges the transition between the hospital

and the home and between professional care, lay care and community care, and from medical definitions to lay definitions. The concept of a career not only incorporates outside structural constraints but it also emphasises individual responsibility, action and initiative.

The admission to hospital signals the abandonment of responsibility of self care to the authority and expertise of the medical profession. In the hospital health status is controlled by chemical or surgical intervention . The discharge from hospital , and the return home, signals the resumption of responsibility for health care. Lay health care management is perceived in terms of diet, rest and exercise as well as following the doctors orders. The concept of the convalescent career is useful in the interpretation of lay health care management because it embodies differences in the stage in the life cycle, differing perceptions of the responsibility for incurring ill health in relation to diagnosis and finally the ability of the individual to implement changes in health care management. The concept of career therefore allows acute ill health to be seen as a series of sequences or stages which are dependent ,to varying degrees on the individual, the hospital and the 'community'. By placing the concept of acute ill health on a stage in the continuum of 'health', acute ill health and health outcomes, attention can be directed not only to preventive health care

counselling but also convalescent care and medical self management. The after care of acute patients is therefore the corner stone in the prevention of the prematurely 'elderly', the disabled and acute depression.

Three central problems of the community care policy emerge as a result of the analysis of the literature and the research. One problem is the dispersal of the patients, which makes them less visible and geographically less accessible. Secondly, it raises problems because of the high visibility, technical and professional care of hospital care compared to lay care, which is dependent on the proximity, interest, knowledge and the ability of the family and community services to provide care. Due to the dispersal of convalescing patients in the community and the structure and organisation of community professional services, care in the community is very much more dependent on the family to initiate, organise and access professional help. The third problem lies in the nature of lay care. It is dependent on the social and economic basis of the family, the quality of family relationships and notions of appropriate health care behavior . Lay health care is generalist in nature and its concepts of health and illness vary with social class and stage in the life cycle. Furthermore, it is precisely over the common lay notions of health care behavior, such as rest, diet and exercise, which are the areas which patients have most difficulty in complying

with 'the doctors' orders. Patients typically adhere to medical prescriptions. However patients had little understanding of the medical nature of the drugs which they were taking or the of possible side effects. Since hospital care is centrally organised and controlled it must be emphasized that care in the community is more variable. Communities are microcosms of the larger society and therefore the resources the individual has access to is dependent on levels of affluence in their neighborhood. This is particularly the case with access to medical care as it is in practice often tied to mundane ,practical considerations such as the availability of a car, the painfulness of a bus trip, or the availability of someone to accompany the patient. In other words, convalescence and health outcomes are not medically controlled but are tied to the material and social basis of society.

The recommendations which this research suggests are concerned with facilitating the flow of communication between the hospital, the community medical community and the patient. The research calls for a revision of the community care policy to explicitly recognise the needs of acute care patients discharged from hospital and to make statutory provision , which is tailored to the needs of individual patients. The needs of short stay acute care patients are just as real as

those of the priority groups and need to be addressed in health and social policy. The close relationship between the likelihood of incurring ill health and social class necessitates a move towards a medical and social model of health in community care policy. Health can not be abstracted from the immediate social and material environment. It must take account of the interacting relationship between stage in the life cycle, material standards and social circumstances and the problems encountered with lay care. Walker [Walker,A.,1982],Townsend and Davidson [Townsend,P. and Davidson,N.,1982] Grundy, [Grundy,E. 1987] and the Audit Commission [Audit Commission, 1986] have all called for a more imaginative approach to the development and delivery of services. This research suggests that due to the tenuous link between the hospital based professionals, and the professionals based in the community health centers, combined with the problems that many patients encounter, a fast effective connection is needed. The hospital discharge letter is a useful, but not a sufficient device, for communicating between the hospital and the community medical services. This could be facilitated by a discharge planning officer, whose responsibility would be to evaluate the social and material circumstances in the home as well as the particular medical needs of the patient. Patients should be evaluated for social service and medical support after discharge. The bridging funds which have been earmarked for the development of greater

coordination between health and social services could usefully be put toward the development of discharge planning officers. The emphasis, in recent years, has been placed on the development and provision of preventive health care services. However the research makes a case for both preventive health care and for medical counselling after discharge. The dominance of the medical profession together with increasing specialisation of knowledge has made for a feeling of greater disparity between lay knowledge and professional knowledge at the same time as the responsibility for care becomes greater.

This research has suggested that acute ill health often leads to problems of acute depression, premature retirement and physical disablement. It suggests that a strict medical definition of ill health is not sufficient in explaining the relationship between the occurrence of ill health, after care and health outcomes. Clearly what is needed in future research is a long term follow up study of patients discharged from acute care wards and the 'health outcomes' of patients in relation to social class.

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Appendix I

Interview Questionnaire:

Main Patient Questionnaire	pp. 1 - 18
Main Carer Questionnaire	pp. 1 - 8
Follow Up Questionnaire	pp. 1 - 5

Patient Details

<u>Name</u>	<u>Date of Birth</u>	<u>Age</u>
<u>Date of Discharge</u>	<u>Date of Interview</u>	<u>No. of Days since Discharge</u>

Address

Informant was : Alone ; Spouse; Children; Other

Introduction

I come from the Open University. We are doing a study of people recently discharged from hospital and the care they receive upon returning home. The aim of the study is to learn more about health care provided by friends and family.

We would like to ask you a few questions after your return home. The questions will take about one hour.

Anything you tell us will of course be treated as confidential- your name will not be published or used at all.

Address to Patient

I understand that you have recently been discharged from hospital.
May I ask you a few questions about your illness?

1. Why were you in hospital ? _____

2. How long were you in hospital? _____
3. What date did you come out of hospital? _____
4. When do you hope to be fully fit again? _____
5. Is this the first time that you have been in hospital for
_____?
6. Have you been in hospital in the last 10 years for anything
else?
1. Yes 2. No

If yes , what ? _____

7. Did you have anyone to contact when leaving hospital ? Circle
all relevant people.

1. Husband 2. Wife 3. Mother 4. Father 5. Son
6. Daughter 7. Friend 8. Neighbor 9. Other _____

7a. What kind of help did you ask of them?

8. Do you have someone to look after you?

1. Yes 2. No

8a. If yes, what is their relationship to you?

1. Spouse 2. Daughter 3. Son 4. Friend

5. Other _____

9. Is this where you normally live?

1. Yes 2. No

9a. If since discharge you are living away from home is this arrangement

1. Temporary 2. Permanent

10. Since leaving hospital have you suffered much pain or discomfort?

1. Yes 2. No

11. Do you have any problems getting about indoors?

1. Yes 2. No

11a. If yes, what sort of problems do you experience? Can you [on your own]

1. Wash 2. Dress 3. Bathe 4. Prepare Meals

If appropriate, How do you manage to have a bath/wash/dress?

12. Do you have any special equipment or gadgets to help you get about or make things easier for yourself?

1. Yes 2. No

12a. If yes, what aids do you have ?

- | | | |
|------------------|-----------------------------|------------------|
| 1. Crutches | 2. Walking stick | 3. Walking frame |
| 4. Wheel chair | 5. Emergency phone | 6. Hearing Aids |
| 7. Ejector chair | 8. Bathing Aids [hand rail] | |
| 9. Toilet rail | 10. Other _____ | |

12b. Who provided it?

- | | | | |
|---------|--------------------|-------------|---------------------|
| 1. Self | 2. Local Authority | 3. Hospital | 4. Voluntary Agency |
|---------|--------------------|-------------|---------------------|

12c. Did you pay towards the cost at all?

- | | |
|--------|-------|
| 1. Yes | 2. No |
|--------|-------|

13. Is there anything related to your stay in hospital which still troubles you?

- | | |
|--------|-------|
| 1. Yes | 2. No |
|--------|-------|

If yes, what?

- | | |
|--------------------|-----------------------|
| 1. Pain/soreness | 2. Sleeplessness |
| 3. Breathlessness | 4. Unsteady feet |
| 5. Giddiness | 6. Hands Trembling |
| 7. Vomiting/Nausea | 8. Weakness/Tiredness |
| 9. Constipation | 10. Diarrhea |
| 11. Incontinence | 12. Other _____ |

14. As a result of your illness are you taking any medications?

1. Yes 2. No

15. What treatment or medicine do you receive at home?

1. None 2. Medicine/tablets
3. Drops;eye/ear/nose 4. Injections
5. Special Diet 6. Special exercises
7. Wearing appliance 8. Other _____

15a. What is the effect of the medicine? [does it have any side effects]

15b. Do you take the 'medicine ' yourself or does a nurse come to you?

1. Self 2. Nurse comes

15c. Were you taking any medicine before your recent illness?

1. Yes 2. No

If yes, please specify _____

15d. Have you been taking the medicine the doctor prescribed?

1. Yes 2. No

16. Do you take any medication other than that prescribed by your doctor?

1. yes 2. No

If yes, please specify _____

17. Will/Do you attend hospital as an outpatient?

1. yes 2. No

18. What are the main problems you are experiencing now you are at home? [eg. still feeling unwell, shopping, bathing]

19. What do you do during the day? [eg. hobbies]

May I ask you a few questions about your general health?

20. Do you smoke cigarettes?

1. Yes 2. No

20a. Do you smoke a pipe?

1. Yes 2. No

20b. If yes have you ever tried to stop smoking?

1. Yes 2. No

21. Do you drink alcohol?

1. Yes 2. No

If yes, about how much would you say?

- | | |
|----------------------|--------------------|
| 1. A little socially | 2. Regularly-daily |
| 3. Quite alot | 4. Too much |

22. What would a typical meal be? What did you have for breakfast, midday meal and evening meal yesterday?

Breakfast

Midday

Evening Meal

23. Is that what you normally eat?

1. Yes 2. No

24. Has the doctor given you any advice about what you should eat; stop smoking or alcohol consumption?

1. Yes 2. No

If yes, please specify _____

25. Do you follow the doctor's advice?

1. Yes 2. No 3. Usually 4. Sometimes

Can you tell me about your education?

26. How old were you when you left school?

- | | |
|----------------|----------------|
| 1. 14 or under | 2. 15 or under |
| 3. 16 or under | 4. over 16 |

26a. If over 16- Did you go on to higher education?

- | | |
|-------------------------|------------------------------|
| 1. Studied for A levels | 2. Further Education College |
| 3. Technical College | 4. Polytechnic |
| 5. University | 6. Other _____ |

27. Are you retired?

- | | |
|--------|-------|
| 1. Yes | 2. No |
|--------|-------|

28. What is your occupation [what was your last occupation]?

Please describe _____

29. Do you have a job at the moment?

- | | |
|--------|-------|
| 1. Yes | 2. No |
|--------|-------|

30. Is it part-time or full-time?

- | | |
|--------------|--------------|
| 1. Part-time | 2. Full-time |
|--------------|--------------|

31. Were you working until you went into hospital?

- | | |
|--------|-------|
| 1. Yes | 2. No |
|--------|-------|

32. Are you on sick leave from work?

1. Yes 2. No

33. Can you tell me what you earn per year? [including tips, overtime]

1. £ 2,000 - 4,000
2. £ 4,000 - 6,000
3. £ 6,000 - 8,000
4. £ 8,000 - 10,000
5. £ 10,000 - 12,000
6. £ 12,000 - 15,000
7. £ 15,000 -

34. Are/were you paid

1. Weekly 2. Monthly

35. Does this include any overtime payment?

1. Yes 2. No

36. Do you have any other source of income?

1. Yes 2. No

If yes, what source? _____

37. Have you lost your job on account of the illness?

1. Yes 2. No

38. Since your hospitalisation has your illness caused you any financial difficulties?

1. Yes 2. No

If yes , please specify _____

39. How would you say that the care you received at home differs from the care you received in hospital ?

40. Were you pleased to be allowed home from hospital ?

1. Yes 2. No

41. We have asked you alot of questions do you have anything that you would like to add?

Part Two;

Address the following questions to the main carer if there is one, otherwise continue with the patient.

May I ask you a few questions about the support you have received since you were discharged from hospital.

1. Have you had any professional help or advice?

1. Yes 2. No

If yes, from whom? and what help did they provide?

<u>Helper</u>	<u>Type of Help/Advice ex. Medical,</u> <u>financial, social support</u>
---------------	---

<u>Doctor</u>	
---------------	--

<u>Nurse</u>	
--------------	--

<u>Occupational/ Physical therapist</u>	
---	--

<u>Health Visitor</u>	
-----------------------	--

<u>Home Help</u>	
------------------	--

<u>Social Worker</u>	
----------------------	--

<u>Meals on Wheels</u>	
------------------------	--

2. Is there any help or advice you would like which is not provided? [what sort of help would be useful?]

3. Have you received any help from voluntary agencies?

1. Yes 2. No

If yes, which? _____

3a. Do you have any private domestic help?

1. yes 2. No

If yes,

1. Daily 2. Weekly

Can you tell me a little about the other members of your household?

4. How many people live with you here? _____

Can you tell me a little about each of them?

Relationship	Sex	Age	Occupation	F/T	P/T
1.					
2.					
3.					
4.					
5.					

[Is the patient;

1. Single 2. Married 3. Separated
4. Divorced 5. Widowed 6. Cohabiting

5. Do you receive any help from your parents?

1. Mother -Yes 2. Mother -No 3. Father-Yes 4. Father-No

If yes, please circle the nature of the help:

1. Advice 2. Financial Help 3. Housework
4. Transportation 5. Shopping 6. Cooking
7. Other _____

6. Do you receive any help from your brothers and sisters?

1. Brother-Yes 2. Brother-No 3. Sister-Yes 4. Sister-No

If yes, indicate the nature of the help.

1. Advice 2. Financial support 3. Housework
4. Transportation 5. Nursing 6. Shopping
7. Cooking 8. Other _____

7. Do you receive any help from your son or daughter?

1. Son-Yes 2. Son-No 3. Daughter-Yes 4. Daughter-No

7a. How far away does he/she live? _____ miles

7b. How often does he/she visit?

1. Daily 2. Weekly 3. Monthly 4. Yearly
5. Other _____

7c. Please indicate the nature of the help.

1. Advice 2. Financial support 3. Housework
4. Transportation 5. Nursing 6. Shopping
7. Cooking 8. Other _____

1. Yesterday 2. Two days ago 3. Last week
4. Longer ago

1. Friend 2. Neighbor 3. Neighbor/Friend
4. Church visitor 5. Other

1. Yes 2. No

1. Shopping	2. Cleaning	3. Cooking
4. Bathing	5. Dressing	6. Transport
7. Other		

1. Advice 2. Financial support 3. Help in the house
[ex. cleaning]

4. Transportation 5. Nursing 6. 'Minding'
7. Bathing 8. Other

.....

12. Is Mr/Mrs/Miss _____ able to do anything for you?

1. Yes 2. No

13. What if any, has been the effect of _____ illness on other members of the family?

Now may I ask you some questions about living in Milton Keynes?

14. How long have you lived in this area ? _____
months/years.

15. Is this property

1. Rented 2. Shared Owner 3. Owner

15a. Do you find the design of this house is suitable to your needs?

1. Yes 2. No

15b. Do you have stairs to climb?

1. Yes 2. No

16. Do you have any problems with the following?

1. Heating 2. Dampness
3. Condensation 4. Leaking Roof

16b. What is the problem? _____

17. Do you have an indoor toilet? 1. Yes 2. No

18. Do you have a car in this household?

1. Yes 2. No

If yes, who is licensed or insured to drive it?

18a. Do you have access to it?

1. Yes 2. No

18b. If no, what method of transport do you use around Milton Keynes?

1. Bus 2. Walk 3. Friend's Car 4. Taxi

5. Other _____

19. If you travel to the doctor or to the hospital out patients department, how do you get there?

Doctor Hospital

1. Own Car

2. Friend/Relative Car

3. Hospital transport

4. Volunteer transport

5. Bus

6. Walking

7. Taxi

8. Other

20. If a friend/relative's car, does he /she have to take time off work?

1. Yes 2. No

21. Do you have a telephone? 1. Yes 2. No

22. Do you have a washing machine? 1. Yes 2. No

Many people find difficulty with paying bills

23. Do you find problems paying your bills?

1. Yes 2. No

Please comment _____

24. Do you think that the bills or expenses have increased since your illness either while in hospital or since your return home?
[eg. prescriptions, car, taxi fares]

1. Yes 2. No

25. Do you think that any of your bills will increase now that you are home from hospital?

1. Yes 2. No

26. What are your major expenses and how much are they?

	<u>per week</u>	<u>per month</u>	<u>per quarter</u>
Housing	_____	_____	_____
Heating	_____	_____	_____
Electricity	_____	_____	_____
Telephone	_____	_____	_____
Transportation	_____	_____	_____
Leisure	_____	_____	_____
Alcohol	_____	_____	_____
Tobacco	_____	_____	_____
Food	_____	_____	_____

27. Do you receive any employment or state benefits?

Yes No Dk Self Spouse Rel. Other

Retirement Pension

Supplementary Ben.

Widows Pension

Unemployment Ben.

Sickness Ben.

Invalidity Ben.

Address to Main Carer

May I ask you a few questions about yourself and your contribution to the after care of _____.

Circle the appropriate answers.

1. What is your relationship to the patient.

1. Wife 2. Husband 3. Daughter
4. Son 5. Relative 6. Other _____

2. Do you normally live here?

1. Yes 2. No

If no, [a] how far away [in miles] do you live?

[b] How long do you intend to stay?

[c] do you visit daily? _____

3. Who told you when he/she would be discharged?

1. Patient 2. Hospital 3. Not contacted
4. Nurse 5. Administrator 6. Auxiliary
7. Other

4. Do you know the reason for Mr/Mrs/Miss going into hospital?

1. Yes 2. No

What was the reason? _____

May i ask you a few questions about yourself?

5. When were you born? _____ So you are how old? _____

5b. How would you rate your health ?

1. Good 2. Fair 3. Poor

5c. Have you had any periods in hospital in the last year?

1. Yes 2. No If yes, what for? _____
-

5d. Have you had any illness during the last few months?

1. Yes 2. No If yes, what? _____

6. How old were you when you left school?

1. 14 or under 2. 15 or under
3. 16 or under 4. over 16

If over 16- Did you go on to higher education?

1. Studied for A levels 2. Further Education College
3. Technical College 4. Polytechnic 5. University

7. If appropriate; Are you retired ?

1. Yes 2. No If yes, what was your last occupation?
-

7b. Are you employed ?

1. Yes 2. No If yes, what is your occupation?
-

7c. Is this part-time or full time?

1. Part-time 2. Full-time

7d. What hours do you work? _____

1. Days 2. Nights

7e. Have you taken a leave of absence to care for _____?

7f. If yes, will the leave of absence affect your income?

1. Yes

2. No

7g. Can you tell me what your last take home salary or wage was?

Weekly _____ Monthly _____ Yearly _____

7h. Did this include any overtime payment?

1. Yes

2. No

8. Do you intend to continue working during the convalescence?

1. Yes

2. No

If yes, do you have to adjust your working hours to fit in with your caring?

1. Work shorter hours 2. take longer lunch breaks

3. Other _____

8a. [if applicable] What sorts of conflicts do you experience between working and caring for _____ ?

9. In what ways do you help the Patient?

Mobility 1. Getting up 2. Moving about 3. Washing/Shaving

4. Dressing/undressing 5. Bathing 6. Toilet

7. Eating/drinking

Household chores 1. Special meals /snacks 2. extra laundry

3. Extra cleaning

Transportation 1. Arranging transport [to hospital, doctor]

2. Driving

Medications 1. Tablets 2. Dressings 3. Injections

4. Making sure he/she takes medicine

5. Arranging for a doctor/nurse to visit

6. Arrange for chiropodist

7. Arrange for special equipment

Food

1. Special diet 2. Feeding

3. Other _____

Exercises 1. Hands 2. Legs 3. Other _____

Organising finances 1. Collect pension 2. Pay Bills

3. Collect Benefits

10. What do you experience out of this list as the biggest problem?

11. Have you had to learn how to do new tasks in order to care for
_____?

1. Yes

2. No

12. What in particular do you feel that you had to learn to do for
Mr./Mrs/Miss _____? [ex. learn to cook, put on a dressing
]

13. Do you find that the patient is still experiencing any of the
following?

1. Pain/Soreness 2. Sleeplessness 3. Sleeping a lot

4. Breathless 5. Giddiness 6. Unsteady feet

7. Tremor of hands 8. Weakness/fatigue 9. Depression

10. Vomiting/nausea 11. Constipation 12. Incontinence

Comment _____

14. Specifically can you tell me whether _____ is ever dangerous [or at risk] in his or her behavior either towards him/herself or others? [for example, starting to cook and then forgetting, falling over]

1. Yes 2. No 3. Don't Know

If yes, please specify _____

15. How much time would you say you spend caring for _____ per day? [on average, including special meals, cleaning]

_____ minutes _____ hours

16. Could you give me a rough breakdown of your day from getting up until evening?

6:00 -8:00 am

8:00 - 10:00

10:00 -12:00

12:00 -2:00 pm.

2:00 - 4:00

4:00 - 6:00

6:00 - 8:00

8:00 - 10:00

10:00- 12:00

17. At present, does _____ have problems in:

Yes No Don't Know

a. Remembering events _____

b. Working out how to do
everyday tasks [dressing,
making tea..] _____

c. Knowing the time _____

d. Correctly naming persons
seen regularly _____

17. Keeping in touch with
a conversation _____

If yes, to any of the previous questions;

a. Has this occurred since the current illness?

1. Yes 2. No

b. Was it already occurring before the current illness?

1. Yes 2. No

18. Do you have to get up during the night to care for _____?

1. Yes 2. No

_____ minutes _____ hours

19. How long can you leave _____ on his/her own?

_____ minutes _____ hours

20. What signs of improvement do you see in _____?

21. How do you think the care you provide is different from hospital care?

22. What sorts of problems do you encounter in providing this after care?

1. Lack of time 2. Neglect of work commitments
3. Lack of strength required for lifting, carrying etc.
4. Neglect of other dependents

23. Do you find it difficult finding time to do all the things necessary for the wellbeing of the patient?

1. Yes 2. No

Comment

24. Hospitalisation is often a period of worry and emotional tensions. What are the main worries at the moment?

25. Do you have any special problems as a result of your worries?

26. How do these feelings affect you and how do you cope with them?

27. Do you have anyone to talk to about these worries?

1. Yes 2. No

If yes, can you speak to them regularly?

1. Yes 2. No

28. Are you feeling more relaxed now that _____ is home?

1. Yes 2. No

Please comment, _____

29. How is it that you came to be a main carer?

1. Spouse 2. Parent 3. Daughter/Son 4. Other

30. Was there someone else who could have taken over the care of _____?

1. Yes 2. No

31. Often people who look after their friends/spouses or relatives have moments of stress and loneliness. Do you experience this?

32. What do you enjoy doing for relaxation? [for example; do you have any hobbies or belong to any clubs] _____

33. I have asked you many questions, is there anything which you would like to add?

Follow Up Questionnaire

Date of interview _____

Date of Follow up interview _____

Name and Address _____

Informant was ; 1. alone 2. Spouse 3. Children 4. Other

1. How are you feeling now?

1. Recovered 2. Adapting to new limitations 3. Poorly

1a. Do you experience any of the following?

1. Sleeplessness 2. Incontinence 3. Unsteady feet
4. Dizziness 5. Depression

2. What are your current needs for care?

3. Are you able to move without difficulty?

1. Yes 2. No

If no. what difficulties are you encountering?

1. Bathing 2. Toilet 3. Dressing/Undressing
4. Shopping 5. Cooking 6. Housework

4. Are you on any medications at the moment? If yes, how many?

For what? 1. _____
2. _____
3. _____
4. _____

5. Have you had any professional help or advice [such as doctors, nurses, occupational therapists, dietician, health visitor, meals on wheels in the last few weeks?

Who Initiated the Contact?

	Self	Professional
Doctor	_____	_____
Nurse	_____	_____
Occupational/Physiotherapist	_____	_____
Dietician	_____	_____
Health Visitor	_____	_____
Meals on Wheels	_____	_____
Home Help	_____	_____

5a. If appropriate; what was their advice?

6. Have you had a hospital or clinic outpatient appointment?

1. Yes 2. No

6a. What was the outcome of the visit ? Do you have another outpatient appointment?

1. Yes 2. No

7. Have you had any help from a volunteer organization , such as the Red Cross?

1. Yes 2. No

If yes, what did they do?

7a. Are you receiving any help from your neighbors?

1. Yes 2. No

If yes, what sort of help?

1. Shopping 2. Cooking 3. 'Looking in'
4. Transportation [ex. to doctor, shopping]
5. Housework 6. Personal care

8. Are you receiving any help from your relatives?

1. Yes 2. No

If yes, from whom?

1. Son 2. Daughter 3. Wife 4. Daughter
5. Son in law 6. Husband 7. Other

8b. What type of care / help are they providing?

-
-
-
1. Cooking 2. Shopping 3. 'Taking out'
4. Transportation 5. Company 6 Personal Care [bathing..]
7. Housework

9. Are you in need of some support or help that you do not have at the moment?

1. Yes 2. No

If yes, what support would be a help?

Now I would like to ask you a few questions about your material circumstances?

10. Would you say that your financial circumstances have altered at all in the last month?

1. Yes 2. No

10a. If yes, how?

1. Greater expenditure eg. a. prescriptions, b. purchase of special furniture, c. special diet d. other _____

2. Greater allowances eg. a. attendance allowance b. mobility allowance c. other _____

Economically Active

3. Have you had to reduce working hours; are you loosing income?

1. Yes 2. No

If appropriate

a. Have you been able to return to work? 1. Yes 2. No

b. Has your main carer/ spouse returned to work? 1. Yes 2. No

4. Has your job or that of your spouse been effected in any way?

Retired

5. Do you receive a pension?

a. Do you receive free prescriptions? 1. Yes 2. No

b. Do you pay for meals on wheels? 1. Yes 2. No

c. Do you receive free meals on wheels? 1. Yes 2. No

d. Do you have a home help free of charge? 1. Yes 2. No

e. Do you have a paid home help?

6. How do you feel that you are coping? [ex. are you able to do household chores?]

1. Yes 2. No 3. Some

7. How are you spending your time?

1. Watch TV 2. Reading 3. Gardening 4. Other _____
-

8. Do you go out?

1. Yes 2. No

If yes where?

1. Cinema 2. Shopping 3. Pub 4. Club 5. Bingo

Comments: _____

9. How is your main carer eg. husband or wife? Have they been to the doctor in the last month?

1. Yes 2. No